Stories of students with autism, their lived experiences and journey throughout education: A narrative analysis

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Acknowledgments

This thesis has taken me on a five-year journey of discovery both academically, emotionally, socially, personally, and professionally. As a schoolgirl, with then undiagnosed autism and ADHD, I faced many challenges, and never imagined that I could one day achieve A-level qualifications, let alone complete a PhD. This thesis would not have been possible without acknowledging the support of all involved.

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Abstract

Students with autism face a multitudinous array of day-to-day internal horizontal transitions, and school-to-school external vertical transitions, during their educational journey. This research explores the educational and lived experiences of five students with autism. Its intentional aim is to promote greater understanding about their unique needs, to positively inform, influence, policy, and practice. To contribute towards the reduction of autistic disabling educational barriers, in turn enabling students to reach their full potential. Narrative analysis methods were used to explore participants unique first-person experiences, to interpret and analyse their fabula, transcribed spoken words, and sjuzet, non-verbal cues, as a means to represent their true reality. Transition and change theory models were adapted as a tool to represent these findings. Case comparisons were made to identify common themes, which were then compared with general and reviewed literature, to gain a comprehensive understanding about the educational experiences of the wider autistic population.

Findings indicated that all participants faced a wide range of academic and emotional-social difficulties, termed concurrent stressors. It was evident that a diagnosis and autism specific support did not guarantee a reduction in stressors and improvement in state of health, due to core autistic features such as co-occurring depression, obsessive phobias, and inescapable social difficulties. All participants experienced the greatest number of stressors and a major deterioration in health, during the secondary phase. All participants experienced a reduction in stressors and improvement in health, during the sixth form phase. The university phase had mixed results with the minority of participants' health deteriorating, or remaining stable, and the majority of participants showing an improvement overall. This research concludes, autism is a lifelong disabling condition, requiring early diagnosis, to ensure that stressors are understood, supported through autism specific support, to minimise deterioration in state of health, and to improve educational, academic, emotional-social, experiences.

Declarations and statements

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed [redacted] (candidate)

Date: 28th April 2022

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s).

Other sources are acknowledged by explicit references. A reference list is appended.

Signed [redacted] (candidate)

Date: 28th April 2022

STATEMENT 2

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

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Confidentiality clause

To maintain confidentiality, an anonymous system of unique coding has been used to label and identify participant data which is only known by the researcher and their supervisor. All names in this thesis have been anonymised through use of pseudonyms or omissions. All documentation has been stored in accordance with data protection laws, storage procedures and in agreement with the requirements set by the Swansea University Medical Research Ethics Sub-Committee.

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Abbreviations

Ac	Academic
ADHD	Attention deficit hyperactive disorder
ASC	Autism spectrum condition
ASD	Autism spectrum disorder
BTEC	Business and Technology Education Council
CCA	Categorical-content analysis
CFA	Categorical-form analysis
CAMHS	Child and Adolescent Mental Health Services
CS	Concurrent stressors
CSS	Concurrent stressor support
CTT	Core transitioning theme
D&D	Differences and difficulties
DCD	Developmental co-ordination disorder
EF	Executive functioning deficits
ES	Emotional-social
EST	Emotional-social transitioning
FE	Further education
GCSE	General Certificate in Secondary Education
HCA	Holistic-content analysis
HE	Higher education
HFA	Holistic-form analysis
IEP	Individual education plan
IS	Insistence of sameness
MaD	Major deterioration (in state of health)
MaI	Major improvement (in state of health)
MiD	Minor deterioration (in state of health)
MiI	Minor improvement (in state of health)
NA	Narrative analysis
OCD	Obsessive compulsive disorder
P	Primary school
RRB	Repetitive restrictive behaviours
S	Secondary school
SE-CSS	Stable, efficacious - concurrent stressor support
SEN	Special educational need
SnC	Sensory challenges
ToM	Theory of mind
TST	Transitioning sub-theme
UBSc	University (undergraduate - Bachelor of Science)
UMSc	University (postgraduate - Master of Science)
WCC	Weak central coherence

Glossary

Key term	*Description of key term*
Autism spectrum condition (ASC) or Autism spectrum disorder (ASD)	A neurodevelopmental condition/disorder referred to as being a spectrum which runs from low to higher functioning levels.
Aspergers	'Higher functioning' autistic individuals who, prior to the publication of the most recent diagnostic guidelines (DSM-V and ICD-11), would have been diagnosed with 'Asperger syndrome'. From a diagnostic perspective this term is no longer in use.
Autism	Referring to individuals with ASC, ASD, Asperger's and/or 'higher functioning' autism.
Change	"*The act of becoming different, or the result of something becoming different*".[1(Cambridge online dictionary)]
Developmental disorder	"*Any disorder present at birth or which first appears in infancy, childhood or adolescence*".[2(p88)]
Executive function	"*…an umbrella term that encompasses various higher-order cognitive processes considered to be necessary for preparing and performing complex goal-directed behaviors in situations in which automatic (habitual) behaviors are not sufficient*".[3(p3089)]
External-Vertical transition	The process of change that an individual goes through moving from one educational phase to another e.g., Pre-school to primary, primary to secondary, secondary to sixth form/FE college, sixth form/FE college to university/HE.[4]
FE	Further education e.g., sixth form school or college
HE	Higher education e.g., university
'Higher functioning' autism	'Higher functioning' is not a medical diagnostic label (hence the use of inverted commas throughout), however it is a term often used in literature to refer to individuals with autism who have moderate to high levels of intelligence with mild or no functional language impairments.
Internal-Horizontal transition	Any process of change that an individual goes through during their educational phase e.g., from a lesson to breaktime, from one lesson to another, from one activity to another, from home to school, from the usual teacher to a substitute teacher, from a sensory free environment to a sensory overwhelming environment. "*Referring to movement across various settings that a child and his/her family may encounter within the same time frame*".[4(p4)]
Neuro-diverse (neuro-divergent)	A term used to refer to a collection of conditions such as ADHD, ASD, dyspraxia, dyscalculia, dyslexia, dysgraphia, Tourette syndrome, anxiety disorders, obsessive-compulsive disorder. "*…a range of developmental, neurological conditions and represents those who are, in some way, 'atypical' and who experience the cognitive and sensory world in a 'different' way*".[5(p9)]
Sixth Form	Refers to the educational phase when A-level or BTEC studies are undertaken aged 16 years plus (following GCSE exams aged 16 years).
Transition	"*A change from one form or type to another, or the process by which this happens*". [6(Cambridge online dictionary)]

Chapter One: Introduction

1.1 Chapter Overview

To gain insight into Autism Spectrum Condition (ASC) this chapter will describe what autism is, a brief history of autism, its diagnostic criteria, prevalence, and the process involved in becoming diagnosed. The differences and difficulties experienced by those with autism will be discussed in terms of neurophysiology, executive functioning, central coherence, psychology, mental health, co-occurring neuro-diverse conditions, and other co-occurring conditions. The unique change and transition difficulties faced by individuals with autism will be examined. Finally, the chapter will conclude by detailing the research question, aims, objectives, the participants involved and the research title.

1.2 Autism terms used in this research

Semantic language in this research has chosen to refer to the ‘individual’ first and their ‘autism’ second, recognising that an individual’s core may be made up of a multitude of diagnostic elements rather than solely autism. This ordering of words aims to encompass all experiences, whether autism related or not in order, to reflect the individual’s holistic lived experience. For example, some individual experiences may be a bi-product of having a co-occurring condition such as ADHD rather than solely due to their autism. It is vital to note that others might have a differing word order preference which I (the researcher) am respectful of and that literature does not definitively agree on what this should be. The ultimate decision to use ‘individual with autism’ word order has been based on my (the researcher’s) personal preference as an individual who has autism, who does not consider autism as the core of my being but as an important piece which contributes towards who I am and my experiences. Thus ‘individual with autism’ will be used throughout rather than conditional-first person language (‘autistic individual’) with the term ‘individual’ or ‘individuals’ being used to refer to individual(s)/student(s) diagnosed with autism spectrum disorder (ASD). Unless referring directly to specific terminology used in the worldwide diagnostic frameworks,[7, 8] the term ‘ASD’ will be replaced with ‘autism’ or ‘autism spectrum condition (ASC)’, with the word ‘disorder’ being replaced with the word ‘condition’. Based on a neuro-diverse ethos of not viewing individuals as less than, lacking or inferior, the terms ‘deficit’, ‘disability’, ‘impairment’, will be replaced with ‘difference’ where appropriate to do so. The intention of this thesis is not to judge individuals’ actions, behaviours, characteristics, differences, experiences, or thoughts, as being inferior or superior to individuals not diagnosed with autism.

1.3 What is autism?

> "*Autism spectrum disorder is characterised by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour, interests or activities that are clearly atypical or excessive for the individual's age and sociocultural context. The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities. Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational, or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities*."[8(p6A02)]

1.3.1 Social communication differences

Wing and Gould referred to autism as having a '*triad of impairments'*,[9] namely "*impairment of social relationships, social communication and social understanding and imagination*".[2(p272)] These social differences are inseparable, each influencing the other, and are present from birth "*but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life*".[7(p50)] Literature demonstrates that individuals have varying degrees of social communication deficits which result in problems interpreting, expressing, spoken and unspoken language to varying degrees, and using their body language and spoken words to express themselves.[9] For example, they may have reduced or excessive eye contact and limited conversational skills, unless involving a topic of interest. Deficits with linguistic processing, interpreting others' body language and spoken word, misinterpreting intent, and taking speech literally, are also evident. Social interaction deficits often result in problems communicating and interacting with peers, teachers, family members and wider society. Thus, core to autism is a lack of social skills,[10] especially the skills needed for social play. Research evidences that individuals appear to not innately acquire the necessary social skills needed during their developmental stages, resulting in them often needing to be taught these.[7, 11-17]

For individuals to be able to interpret others' mental states, actions, see things from another's point of view, research theorises that an efficient network of mirror neurons are needed (to be discussed further in section 1.6), which are believed to be less efficient in an individual's brain.[18] Individuals also demonstrate varying degrees of social imagination difficulties and differences which some researchers claim are caused by lack of theory of mind (ToM), although not universally accepted by all researchers,[19] resulting in difficulties with social perception, imagining another person's perspective, and understanding that others have thoughts and perceptions that differ from their own (sometimes referred to as 'mind-blindness'). These researchers hypothesize that individuals lack the usually innate social cognitive developmental skills, which are normally acquired by around the age of four years.[18, 20-22]

1.3.2 Restricted repetitive behaviours

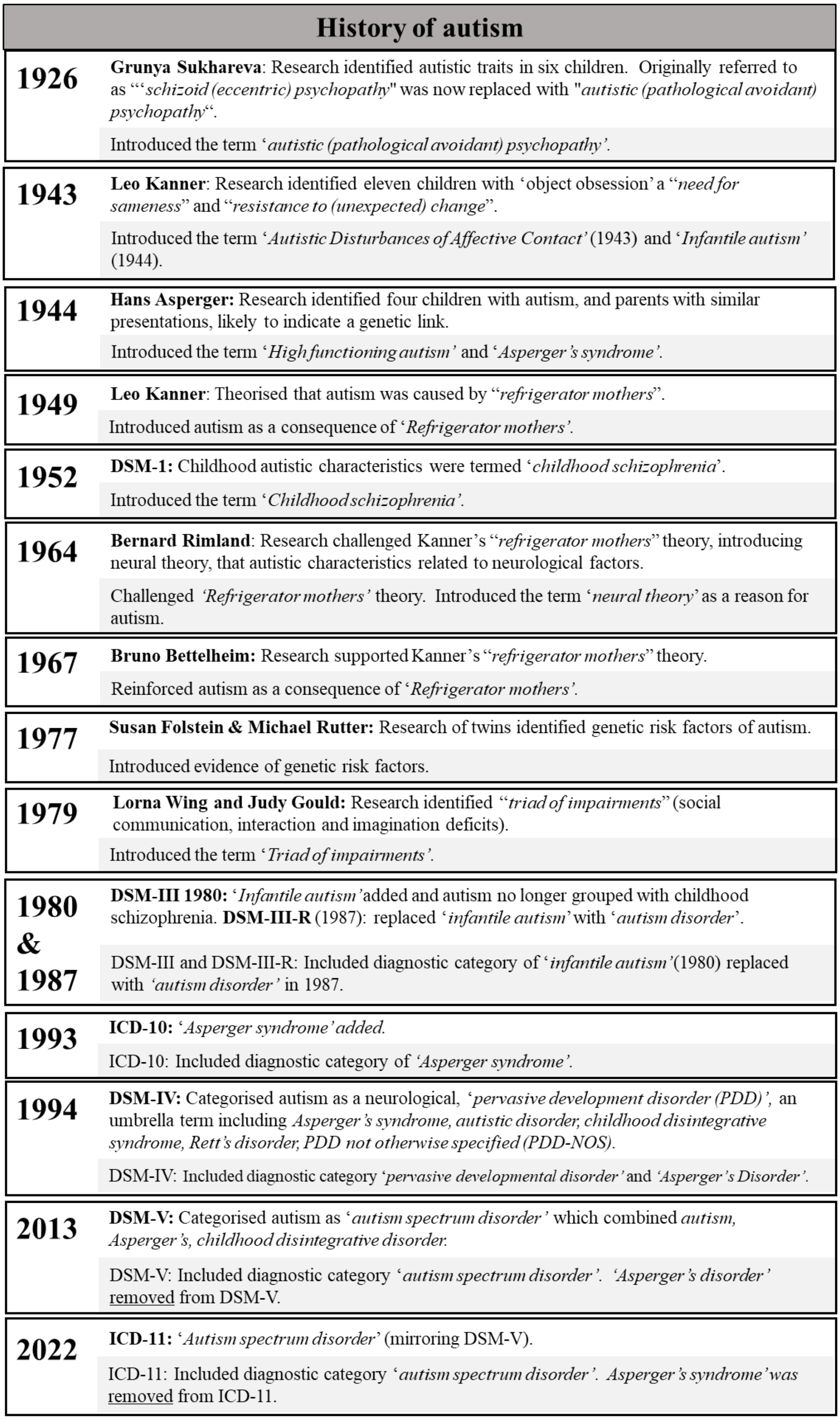
Restricted repetitive behaviours (RRB) are common for individuals. Literature demonstrates that individuals also present with other secondary behaviours such as insistence of sameness (IS) and obsessive interests,[7, 23, 24] as well as sensory, emotional and motor skill differences and difficulties (D&D).[7, 24] IS and inflexibility are believed to be the reason why individuals find change and transitions difficult.[7, 8] Research evidences that RRBs are often triggered by D&D associated with anxiety, stress, attention, change, transition, cognition, emotional regulation, executive functioning (EF), language processing, mental health (MH), receptive language, self-esteem, sensory processing, social behaviour and social language.[25]. RRB's are sometimes referred to as 'abnormal', 'stimming' (self-stimulating), or 'challenging' behaviours in literature.[26, 27] These can take the form of repetitive motor movements such as arm flapping, spinning, clapping, particularly in the younger years and are usually outgrown for 'higher functioning' individuals.[28-30] Other behavioural D&D mentioned in literature as also co-occurring for individuals are echolalia[7, 23, 30] the repetition of words and phrases, and pica,[31-36] the eating of non-food items.

1.4 A brief history of autism

The term ‘autistic’ first appeared in the literature in the 1920’s when Sukhareva[37] used ‘*autistic pathological avoidant psychopathy*’ to describe children we now believe to have ASC. Research continued, and in the 1940’s Kanner[38] described children with the condition as having a fixation on certain objects, liking routine and struggling to accommodate unexpected changes to that routine. Also, in the 1940’s, Asperger[39] published research that first described children with the condition that were ‘higher functioning’ and of average to above average intelligence. He was also one of the first researchers to suggest that autism had a genetic link, after documenting how parents presented with similar characteristics to their ‘*Asperger*’ child.[39] This finding was later, supported by Folstein et al[40] who evidenced the occurrence of genetic risk factors in their twin studies. In 1979 Wing and Gould’s research[9] introduced the term ‘*triad of impairments*’ to describe social communication, interaction and imagination deficits amongst individuals.

When it came to hypothesizing about the causes or reasoning for the condition, Kanner[41] proposed that autism was caused by ‘*refrigerator mothers*’ or mothers that were seemingly cold and uncaring which resulted in trauma to their child. Whilst there is some that supported this notion,[42] others, such as Rimland,[43] challenged it and introduced a different idea, that the cause had neural roots.

The American Psychiatric Association’s (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM-V)[7] and the World Health Organisation’s (WHO) International Classification of Diseases (ICD-11)[8] sections on mental, behavioural or neurodevelopmental disorders, are the current diagnostic manuals used for ASC by medical assessors worldwide. In 1952 the first version of DSM[44] was created. At this point, autism was classified under the medical term of ‘*childhood schizophrenia*’.[44] It wasn’t until the 1980’s, when versions of the DSM-III were published in 1980 and 1987, that the condition was separated from this grouping and given its own diagnostic term, that of ‘*infantile autism*’[45] which was then changed seven years later to ‘*autism disorder*’.[46] In 1993, almost 50 years after Asperger’s initial reports, the term ‘*Asperger*’*s syndrome*’ was included in the ICD-10[24] and a year later, in 1994, ‘*Asperger*’*s disorder*’ was included in the new DSM-IV[47] manual. Finally, in 2013, ‘*autism spectrum disorder’* or ASD became the new diagnostic label in the DSM-V,[7] which combined the previously separate diagnostic categories of ‘*autism*’, ‘*Asperger*’*s disorder*’, with ‘*Asperger*’*s*’ no longer being used as a diagnostic label in the USA. It wasn’t until 2022, that this was mirrored in the UK, through the updated ICD-11[8] which saw the removal of the diagnostic labels of ‘*autism*’, ‘*Asperger syndrome*’, ‘*pervasive developmental disorder - not otherwise specified (PDD-NOS)*’, replacing them with ‘*autism spectrum disorder’* or ASD.[8] History of autism and terminology is illustrated in figure 1.1.



History of autism	
1926	**Grunya Sukhareva**: Research identified autistic traits in six children. Originally referred to as “‘*schizoid (eccentric) psychopathy*" was now replaced with "*autistic (pathological avoidant) psychopathy*“. Introduced the term ‘*autistic (pathological avoidant) psychopathy’*.
1943	**Leo Kanner**: Research identified eleven children with ‘object obsession’ a “*need for sameness*” and “*resistance to (unexpected) change*”. Introduced the term ‘*Autistic Disturbances of Affective Contact’* (1943) and ‘*Infantile autism’* (1944).
1944	**Hans Asperger:** Research identified four children with autism, and parents with similar presentations, likely to indicate a genetic link. Introduced the term ‘*High functioning autism’* and ‘*Asperger’s syndrome’*.
1949	**Leo Kanner**: Theorised that autism was caused by “*refrigerator mothers*”. Introduced autism as a consequence of ‘*Refrigerator mothers’*.
1952	**DSM-1:** Childhood autistic characteristics were termed ‘*childhood schizophrenia*’. Introduced the term ‘*Childhood schizophrenia’*.
1964	**Bernard Rimland**: Research challenged Kanner’s “*refrigerator mothers*” theory, introducing neural theory, that autistic characteristics related to neurological factors. Challenged *‘Refrigerator mothers’* theory. Introduced the term ‘*neural theory*’ as a reason for autism.
1967	**Bruno Bettelheim:** Research supported Kanner’s “*refrigerator mothers*” theory. Reinforced autism as a consequence of ‘*Refrigerator mothers’*.
1977	**Susan Folstein & Michael Rutter:** Research of twins identified genetic risk factors of autism. Introduced evidence of genetic risk factors.
1979	**Lorna Wing and Judy Gould:** Research identified “*triad of impairments*” (social communication, interaction and imagination deficits). Introduced the term ‘*Triad of impairments’*.
1980 & 1987	**DSM-III 1980:** ‘*Infantile autism’* added and autism no longer grouped with childhood schizophrenia. **DSM-III-R** (1987): replaced ‘*infantile autism*’ with ‘*autism disorder*’. DSM-III and DSM-III-R: Included diagnostic category of ‘*infantile autism’*(1980) replaced with *‘autism disorder’* in 1987.
1993	**ICD-10:** ‘*Asperger syndrome’ added.* ICD-10: Included diagnostic category of *‘Asperger syndrome’*.
1994	**DSM-IV:** Categorised autism as a neurological, *‘pervasive development disorder (PDD)’,* an umbrella term including *Asperger’s syndrome, autistic disorder, childhood disintegrative syndrome, Rett’s disorder, PDD not otherwise specified (PDD-NOS).* DSM-IV: Included diagnostic category ‘*pervasive developmental disorder’* and *‘Asperger’s Disorder’*.
2013	**DSM-V:** Categorised autism as ‘*autism spectrum disorder’* which combined *autism, Asperger’s, childhood disintegrative disorder.* DSM-V: Included diagnostic category ‘*autism spectrum disorder’*. *‘Asperger’s disorder’* removed from DSM-V.
2022	**ICD-11:** ‘*Autism spectrum disorder*’ (mirroring DSM-V). ICD-11: Included diagnostic category ‘*autism spectrum disorder’*. *Asperger’s syndrome’ was* removed from ICD-11.

Figure 1.1: History of autism and terminology.[7-9, 24, 37-47] DSM=Diagnostic and Statistical Manual of Mental Disorders, ICD=International Classification of Diseases.

1.5 Diagnostic criteria

1.5.1 Current diagnostic criteria in the UK

In the UK, the National Institute for health and Clinical Excellence (NICE) works closely with supporting organisations, such as the National Autistic Society (NAS), Royal College of Nursing (RCN), providing autism guidance for best practice. NICE[48] recommends that the foundation of an autism assessment follows the diagnostic criteria of ICD-10,[24] being replaced by ICD-11[8] or DSM-V.[7] At the time of writing this thesis the UK autism assessors were using DSM-V,[7] as a guide, awaiting the implementation of ICD-11[8] in 2022, which will mirror DSM-V,[7] using '*autism spectrum disorder'* as an umbrella term.

Current autism assessment, which involve specific diagnostic questionnaires, use algorithms based on the previous ICD-10,[24] DSM-IV[47] and current DSM-V.[7] These gather specific autism related information, around the core domains of social-communication deficits and restrictive repetitive behaviours, which can then be used to evidence whether an autism diagnosis is applicable or not. Commonly used in the UK are DISCO (Diagnostic Interview for Social and Communication Disorders),[49] ADOS-2 (Autism Diagnostic Observation Schedule, Second Edition),[50] ADI-R (Autism Diagnostic Interview - revised).[51] DISCO focuses on developmental behaviour and abilities across the life span, gathering evidence from the individual and others, such as a parental figure.[49] ADOS-2 focuses on current behaviour and abilities, assessing social communication, interaction, play and/or imagination.[50] ADI-R focuses on behaviour, social interaction, communication, language, restricted, repetitive behaviours, and interests.[51] It is important to note that all questionnaires are not used in isolation, they are combined with a variety of psychological methods such as observations, and other assessment tools.

During the assessment process, assessors will screen for other conditions to identify whether a differential diagnosis is required. Conditions considered are, neurodevelopmental disorders such as dyspraxia/developmental co-ordination disorder (DCD) or global developmental delay (GDD), as well as mental health, or behavioural disorders such as ADHD and attachment disorder. Regressive developmental disorder such as Retts, sensory disabilities such as a hearing impairment, medical or genetic disorders such as genetic abnormalities, and functional disorders such as eating disorders are also screened. Further information on these conditions can be found in DCM-V and ICD-10.[7, 24]

When a diagnosis of Autism Spectrum Disorder (ASD) is made, it is graded according to the exact nature, level or severity of the individual's social communication and restricted repetitive behavioural difficulties. The DSM-V[7] assessment criteria categorises ASD from level one to three, with level one individuals seen as having a mild form of the condition and requiring the lowest levels of support. Level two and three individuals said to require "*substantial support*" or "*very substantial support*" respectively.[7(p52)] It also asks the assessor to specify whether the individual has accompanied or has associated (1) intellectual impairment, (2) language impairment, (3) another neurodevelopment, mental, or behavioural disorder, (4) catatonia and (5) another known medical or genetic condition or environmental factor. Similarly, the ICD-11[8(p6A02)] categorisation places those assessed as having ASD into one of five groupings according to not having or having a disorder of intellectual development and an absence or presence of impairment of functional language or, in the most severe cases, a complete absence of functional language.

1.5.1.1 How should sensory differences and difficulties be included?

The DSM-V[7] includes sensory hyper or hypo sensitivities in the context of RRB diagnostic criteria.

> "*Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement*"[7(p50)]

This is not included in the UK's ICD-10[24] or new ICD-11[8] diagnostic criteria.[8, 24, 52] Robertson et al[53] emphasised the importance of sensory processing being viewed as a primary autistic characteristic, rather than a secondary characteristic, due to its prevalence and impact on individuals socially, behaviourally, as well as its relationship with their social brain and cognitive empathy. The DISCO[51] questionnaire does however examine sensory abnormalities, with Leekam et al[54] evidencing 90% of individuals' experience these throughout their lives, usually affecting at least two sensory domains. Vision, smell and taste have been indicated in research as being the most common senses affected.[49, 54, 55] Kern et al[56] identified individuals had abnormal auditory, visual, tactile and oral sensitivity, and with the exception of tactile sensitivities, all of these improved with age. Oral hyper-sensitivity was found to be greater for individuals, compared with non-autistic peers, with research indicating that this often resulted in food selectivity or the refusal to eat certain flavours and textures of foods.[57] Manning et al[58] investigated autistic childrens' visual perception of moving objects. Their findings indicated that this was more intense for them, suggesting that this hyper-visual focus was likely to be one of the reasons why sensory overload occurred.

In general, literature indicates a strong link between sensory difficulties, mental health conditions and quality of life.[59, 60] However, Spain et al[61] systematic review concluded that greater sensory abnormalities and RRB were not linked with increased social anxiety. Mazurek et al[62] research demonstrated a connection existed between greater sensory over-responsiveness and increasing levels of anxiety, and that an increase in both also increased the severity of gastrointestinal issues. Wigham et al[63] investigated the relationship between sensory abnormalities, anxiety and RRB. Their findings suggested that hypo-sensitivity (less sensory signals) triggered anxiety which then resulted in RRB as an attempt to cope with the anxiety.[63] Sensory abnormalities are also believed to impact social development and contribute towards individuals' social D&D.[64] Engel Yeger et al[65] pointed out a negative correlation between increased sensory D&D and 'higher functioning' individuals lack of ability to perform daily routines. Fernandez-Prieto et al[66] demonstrated that improvement in executive functioning (EF) abilities mediated, sensory abnormalities and socially competent behaviours, especially when EF areas of emotional regulation and control abilities improved.

1.5.2 Prevalence

Data on the prevalence of autism in the UK is limited. Brugha et al[67] indicated that approximately 1.1% of the UK population have autism, although the size of participants in this survey was low and UK coverage limited. Recent data from Northern Ireland (2020) on the number of children with autism is 4.2%. This increase is thought to be due to improvements in data collection as well as understanding about this condition resulting in greater referrals and assessments.[68] Data from the USA (2013) reports autism prevalence as 1.8%.[69] Data from Australia (2018) reported autism prevalence as 1.3%.[70]

Literature highlights that often individuals camouflage their autistic characteristics, as an attempt to appear normal, to fit in with their peers, not wanting to come across as an autistic stereotype, and that this results in lack of referral for diagnosis. Camouflaging also appears to result in individuals' experiencing difficulties with their own self-perception as well as exhaustion from suppressing their natural characteristics.[71] Both UK, USA and Australia report a higher proportion of males having autism in relation to females, ranging from 1.5 times more likely to 5.8 times more likely.[67-70] It is hypothesized that 'higher functioning' autistic females, compared with males, are especially good at camouflaging their social D&D,[72] as well as having a greater linguistic ability to mask their D&D.[73] Loomes et al[74] meta-analysis of approximately 13.8 million individuals, discovered a disproportionate difference between male and female autistic diagnosis at a ratio of 3:1. They suggested another reason that female autism is not diagnosed efficiently is due to autism assessment questionnaires being male orientated, resulting in females not meeting the assessment criteria to be able to get an autism diagnosis as easily or as quickly as a male would.

Literature indicates sociodemographic and economic factors, such as income, ethnicity, parental education and race can influence the ability to access and navigate the assessment system and, ultimately, impact the demographic profile of the prevalence seen.[75] Research indicates that when parents have greater understanding about autism characteristics then this appears to result in larger clusters of autism cases in certain areas,[76, 77] which is presumably due to the positive impacts of raising awareness.

1.5.3 Starting the process and becoming diagnosed

A recent report from the British medical association (2019) refers to the autism diagnostic process in the UK as "*failing a generation*"[78(p1)] and that "*the potential impacts of a delayed diagnosis on a child's development are alarming*".[78(p2)] They criticise the long waiting times for the first appointment, a lengthy diagnostic process involving many assessment stages (figure 1.2), and the further delays between assessment completion and receipt of the final diagnosis.[78]

Autism diagnostic services throughout the UK appear to vary greatly in the provisions offered and support received. Kennedy et al[79] estimated that there was an approximate waiting time of 1-2 years for the initial assessment appointment. Following the first assessment appointment the individual then goes through an autism assessment period involving several key individuals, professionals, which can take a considerable amount of time.[78] It is important to note that, literature indicates that prior to this initial appointment there are also considerable delays due to lack of autism awareness within the educational establishment as to who are responsible for initiating the referral to the autism assessing team. Crane et al[80] UK findings revealed that; "*the average delay between concerns first being noted and the child receiving a diagnosis of an ASD was 4.6 years. The delay between the parent initially contacting a health professional and the child receiving a formal diagnosis was 3.6 years*".[80(p157)]

In the UK according to NICE (2011) guidelines there should be a single point of referral to a specialist autism assessing team, every nation and local authority appear to have variations on this approach.[48] In general, autism referrals tend to predominantly occur via the school for school aged children[81] and involve multifarious elements (figure 1.2 left side). Referrals to autism assessment teams are made through the school's special educational needs co-ordinator (SENCO) or additional learning needs co-ordinator (ALNCo), upon the request of parents or teachers. Literature illustrates that referral is unlikely to occur unless multiple parties, the parents, the teachers, the SENCO/ALNCo, provide evidence of concern and that the greater the concern, the greater the chance of being referred.[82] However, even when referred not all children go on to receive an autism diagnosis the first time they are assessed[77] and they may go on to be diagnosed several years later,[77] delaying their autism specific support.

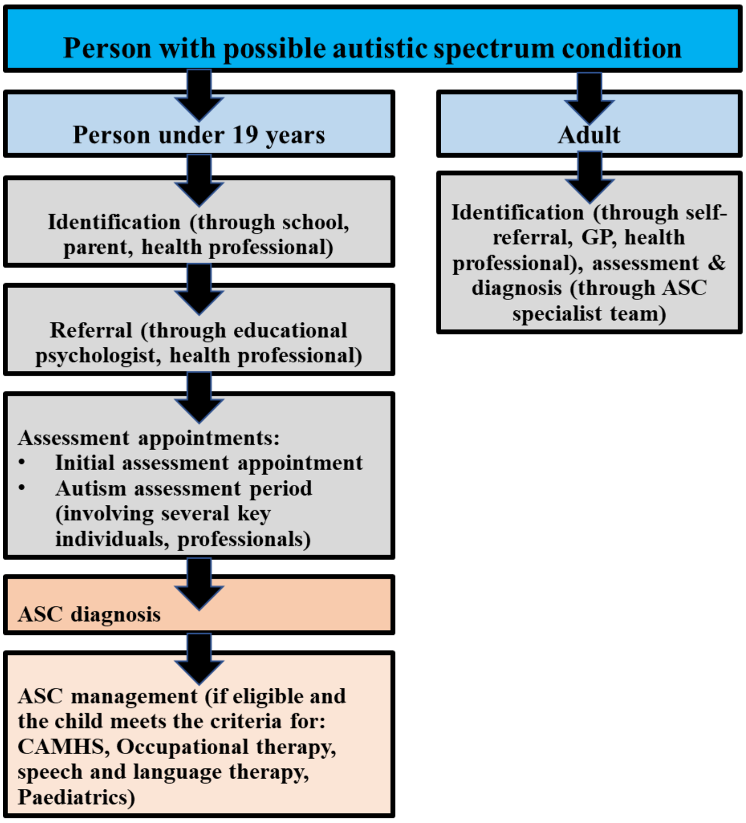


Figure 1.2: Autism spectrum condition referral process for children (<19 years) and adults (>19 years) in the UK. Adapted from: NICE[48]

1.6 Literature, autism, co-occurring differences and difficulties

1.6.1 Neurophysiology

Minshew and Williams (2007) summarised the neurobiological features of autism, how an individual's central nervous system is impacted by this condition. Differences ranged from neuro-connectivity, to pre-frontal cortex-white matter-physiological differences, to brainstem, cerebellar differences.[83] Khalil et al[84] described what they termed the 'social autistic brain' as being physiologically, functionally, and neurologically different. Baron-Cohen et al[85] supported previous findings, that an individual's brain has amygdala differences, the part of the brain responsible for emotional responses to stimuli. Schultz et al[86] referred to the amygdala as the "*central meditor of temporal and frontal lobe systems as they participate in processes critical to social functioning*",[86(p12)] hypothesizing that differences here caused emotional response differences and difficulties (D&D) as well as D&D processing social stimulus. Research involving neuroimaging of individuals' brains hypothesizes that frontal lobe differences result in executive functioning (EF) D&D, particularly due to pre-frontal cortex D&D, which is responsible for an efficient working memory, affective and social behaviour.[86] Differences in an individual's limbic systems, as well as cerebellum, are hypothesized in research to result in social D&D, affective D&D and restrictive repetitive behaviours (RRB),[86, 87] which were described in more detail earlier. Differences in an individual's cerebellum is believed to not only impact motor processing but also social and autobiographical cognition and function.[87, 88] Lastly, research indicates that the greater the differences in an individual's mirror neuron systems and white matter-structure (frontal lobe), compared with a non-autistic peer, the greater the severity of their D&D.[89] As mentioned previously in the context of social imagination, individuals are believed to have an inefficient impaired, system of mirror neurons,[90, 91] likely to cause their social D&D.[92-95] This is assumed to impact all aspects of social interaction, emotional and empathetic responses, as well as theory of mind (ToM).[96] More recent research of Chan et al[97] indicates key mirror neuron D&D for individuals when they perceive another's every day actions, when they perceive emotional-social actions, and that their mirror neuron D&D improve with maturity, which may explain why social D&D often lessen with age.[97] These physiological, functional, and neurological, differences are illustrated in figure 1.3.

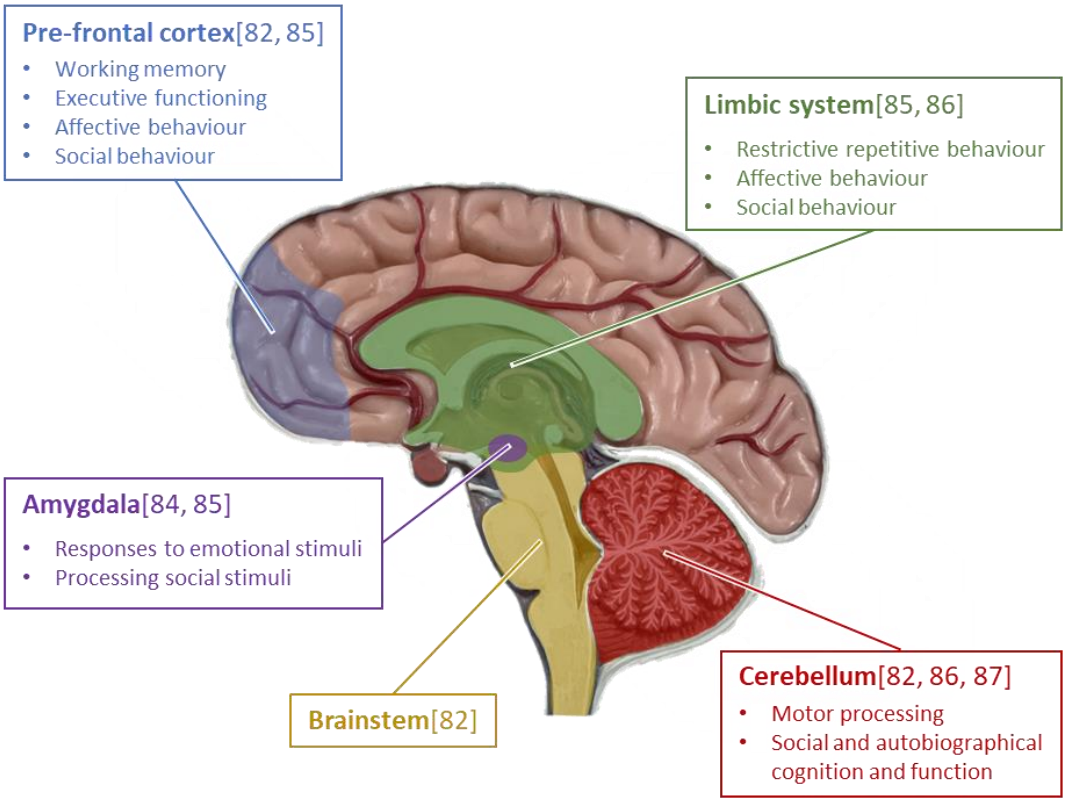


Figure 1.3: A cross-section of the brain showing the regions that have been shown to exhibit physiological, functional, and neurological differences amongst individuals with autism. Bullet points indicate when specific functional differences have been demonstrated. Image produced by Dr Claire Vogan.

1.6.2 Executive functioning

Executive functioning (EF) plays a major role in individuals' D&D and will be referred to throughout this thesis. In general EF is "…*an umbrella term that encompasses various higher-order cognitive processes considered to be necessary for preparing and performing complex goal-directed behaviors in situations in which automatic (habitual) behaviors are not sufficient*".[3(p3089)] Figure 1.4 illustrates the elements that make up, what is termed, an EF 'disorder'.[98] All individuals will have varying degrees of EF D&D,[66, 99] that require support and these will continue into adulthood.[100] Neuroimaging evidences that EF D&D results from pre-frontal lobe differences, resulting in an inefficient working memory and D&D with affective and social behaviour.[86] Geurts et al[101] emphasised that individuals have greater EF D&D when compared with individuals without autism. That it is important to understand what specific EF D&D an individual has, as these will be unique for every individual, requiring individualised specific support.[101]

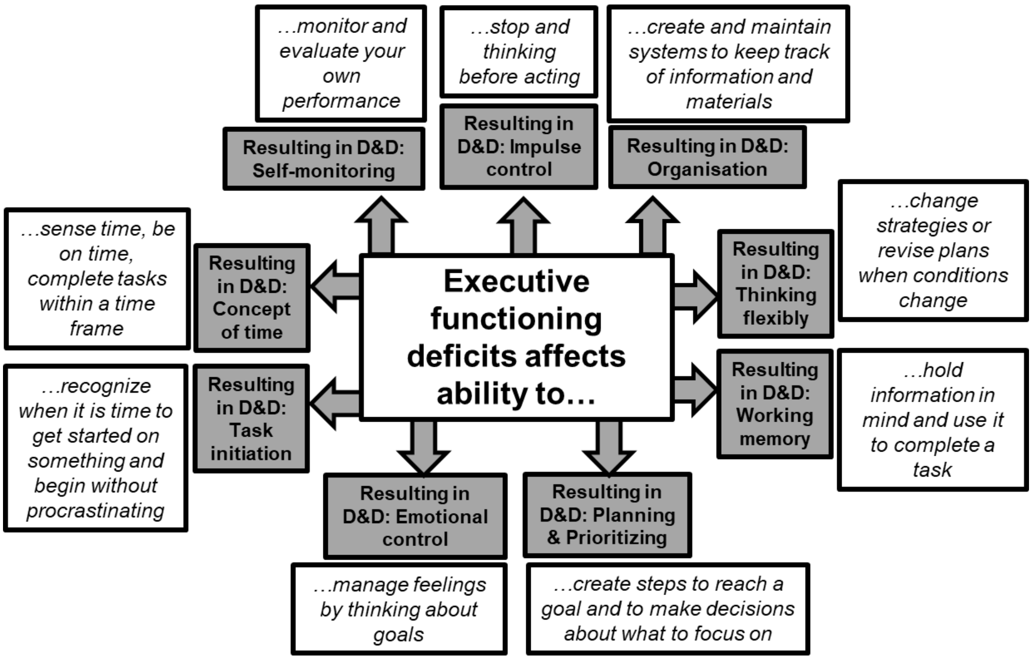


Figure 1.4:Differing effects of executive functioning deficits within the autistic brain. Adapted from: The National Center for Learning Disabilities.[98] D&D = Difficulties and differences.

Hass et al[102] pointed out the complex nature of the term EF, how there is often disparity in literature about its exact meaning. Due to EF being a characteristic of autism it is vitally important to understand its definition and how EF D&D relate to each individual in the context of academic and emotional-social experiences. Literature evidences that EF D&D negatively impact individuals' academic abilities, literacy and overall academic achievements.[103] As noted in Dijkhuis et al[104] individuals' academic success in higher education (HE) is dependent on the EF D&D that they experience and how this often results in them dropping out of HE. Of importance for later chapters in this thesis, figure 1.4 illustrates the ranges of affects those that have difficulties with EF can cause. Finally, research indicates that EF is linked with many other domains such as sensory processing and behaviour regulation,[66] theory of mind (ToM) and weak central coherence (WCC).[105-107] Improvement in EF D&D have been found to improve emotional regulation, sensory D&D, social competence[66] as well as social imagination abilities and ToM.[107, 108]

1.6.3 Weak central coherence

In the context of individuals, some researchers refer to them as having weak central coherence (WCC), such as D&D generalising situations and processing information to gain general meaning, focusing instead on specific details within situations.[109] Kanner[12] referred to WCC as an inability to experience things as a whole, how individuals have an obsessive focus on parts and insistence for sameness (IS). Reid[110] supported Kanner's (1943) ideas, stating that cognitive D&D, such as WCC, particularly inflexibility, results in individuals finding it difficult to adapt to changes, new experiences. It is well documented that cognitive D&D, managing change, triggers anxiety, stress and that this has the potential to result in more serious mental health (MH) conditions.[15, 16, 111, 112]

1.6.4 Psychological

Social vulnerability, a psycho-social construct, appears to be particularly prevalent for individuals.[113] Research suggests that individuals with high IQs have less psycho-social skills and that they are less psycho-socially mature, compared with their non-autistic peers, resulting in them being seen as having a lower psycho-social age,[114-116] that these individuals often do not meet their developmental milestones based on their chronological age.[114-116] Research evidences that individuals have D&D conceptualising themselves, their self-concept and self-understanding.[117-120] In McCauley et al[121] individuals demonstrated that they lacked academic self-concept, or their perception of their own academic capability, when discussing their reading ability. Academic self-concept and understanding one's academic ability are both believed to be linked to one's academic success.[121] Difficulties with gender self-concept for individuals is also demonstrated in research.[122]

1.6.5 Mental health

Throughout literature it is evidenced that individuals commonly have co-occurring mental health (MH) conditions.[123, 124] They frequently experience higher levels of anxiety,[125-130] with the intellectually more able individuals being at a greater risk of experiencing anxiety when compared with ‘lower functioning’ individuals.[131, 132] Research indicates that when an individual has higher levels of RRB, that this is often a sign of increasing anxiety,[95] triggered by fears, phobias, changes, sensory environments, and social D&D.[133, 134]

Specific phobias are very common for individuals,[7, 24, 135] such as phobias related to animals,[134] foods,[136] with unusual fears such as environmental disasters and those that are weather related.[134] Social phobias are also particularly common for individuals[135] and are documented as worsening with age.[30] Although less commonly reported, depression is noted as co-occurring amongst individuals in some studies.[123, 128, 129, 137-139] These studies report differing prevalence of co-occurrence ranging between 10-37%,[123, 128, 129, 137] with those diagnosed later in life being at more risk of developing the condition.[138] However, studies also report a positive correlation between improvement in D&D and a reduction in depressive symptoms.[139]

Eating disorders (ED), which take a variety of forms, are documented as occurring in many individuals, particularly food selectivity.[136, 140, 141] Some researchers hypothesize that children presenting with ED may have undiagnosed autism.[142] Others suggest that autistic characteristics may actually trigger ED such as anorexia.[143, 144] This they say is due to sensory abnormalities and obsessive thoughts causing food restrictions which eventually present as the ED.[143, 144]

A co-occurrence of obsessive compulsive disorder (OCD) is evidenced in literature,[145-147] with prevalence ranging between 9-37% of individuals.[123, 129] This condition, they say, is likely to be triggered by the core autistic characteristics of “*insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior and highly restricted, fixated interests that are abnormal in intensity or focus*”.[7(p50)]

Sleep disorders are also common for individuals,[148, 149] with between 50-80% of individuals documented as experiencing sleep D&D.[150-153] Researchers noting how lack of sleep is likely to trigger challenging behaviours.[150, 153, 154]

Finally, researchers stated that self-harming was significantly greater for individuals, and that self-harming behaviours increased the risk of suicide,[155-157] particularly when the individual has co-occurring MH conditions.[158, 159] Literature evidenced that individuals had a 72% likelihood to display risk markers of potential suicidality (compared with 32% of non-autistic peers),[155, 160] as well as a greater predisposition for suicidal ideation and completing suicide.[161, 162]

1.6.6 Co-occurring neuro-diverse conditions

Individuals commonly have co-occurring neuro-diverse conditions.[7, 163] Attention deficit hyperactive disorder (ADHD), has wide ranging reported prevalence of co-occurrence in the literature, of between 5-75% of individuals[7, 123, 129, 164, 165] with the higher percentages reported from ‘higher functioning’ individuals.[166] Dyspraxia, also known as developmental co-ordination disorder (DCD), presents with very similar characteristics to autism[167] with some research suggesting that as many as 95% of ‘higher functioning’ individuals also having this condition.[168] Approximately a sixth of individuals are diagnosed with co-occurring dyslexia,[169] with an even smaller minority diagnosed with dyscalculia[170] and Tourette’s.[171]

1.6.7 Other co-occurring conditions

Studies have reported, <10% of individuals suffering from epilepsy,[172, 173] psychosis,[174, 175] and post-traumatic stress disorder (PTSD).[176, 177] However in terms of PTSD, some studies hypothesize that individuals are at a greater risk of social victimisation and trauma which may lead to PTSD symptoms, with a 32% greater risk of PTSD following trauma compared to 4% risk for non-autistic peers.[178] A small proportion of individuals without autism who are diagnosed with borderline personality disorder are believed to exhibit autistic traits,[179] due to a similar presentation of emotional and social interaction D&D,[180] particularly D&D in terms of social understanding, emotional responsive, interpersonal skills.[181]

1.7 Change and transition for those with autism whilst in education

Change can be defined as an "*act of becoming different, or the result of something becoming different*"[1(Cambridge online dictionary)] and transition as "*a change from one form or type to another, or the process by which this happens*".[6(Cambridge online dictionary)] The mental flexibility or adaptability needed for successful change and transition are challenging for all individuals due to their core diagnostic behaviours, their "*insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior. Highly restricted, fixated interests that are abnormal in intensity or focus*",[7(p50)] and their "*range of restricted, repetitive, and inflexible patterns of behaviour, interests or activities that are clearly atypical or excessive for the individual's age and sociocultural context*".[8(6A02)]

Individuals transitioning throughout education face a proliferation of change and transitioning experiences. External-vertical transitioning is described as the process of change that an individual goes through moving from one educational phase to another.[4, 182] For example from primary to secondary, secondary to sixth form college, sixth form college to university. The majority of autism transitioning research focuses on these external-vertical transitions, with studies tending to emphasise the importance of specialised autism support and understanding during this transition, documenting the disparities that exist for individuals and looking at what happens when transitioning support doesn't meet the unique transitioning needs of the individual.[4, 183]

By contrast, internal-horizontal transitioning is described as the process of change that an individual goes through on a day-to-day basis.[4] For example, changing from a lesson to breaktime, from one lesson to another, from one activity to another, from home to school, from the usual teacher to a substitute teacher, from a sensory free environment to a sensory overwhelming environment. Research on the internal-horizontal transitioning experiences of individuals is sparce, but important as noted by Twomey because "*for the child with autism, momentary changes defined as horizontal transitions are as challenging and important as changes in children's life trajectories (vertical transitions)*".[184(p58)] Twomey goes on to evidence that individuals had better overall outcomes when their “*daily horizontal transitions were adapted*”,[184(p60)] to meet their unique transitioning needs.

Linking with previous sections, figure 1.5 summarises that characteristics and co-occurring conditions that have the potential to impact the transitioning experiences of individuals during their educational journey.

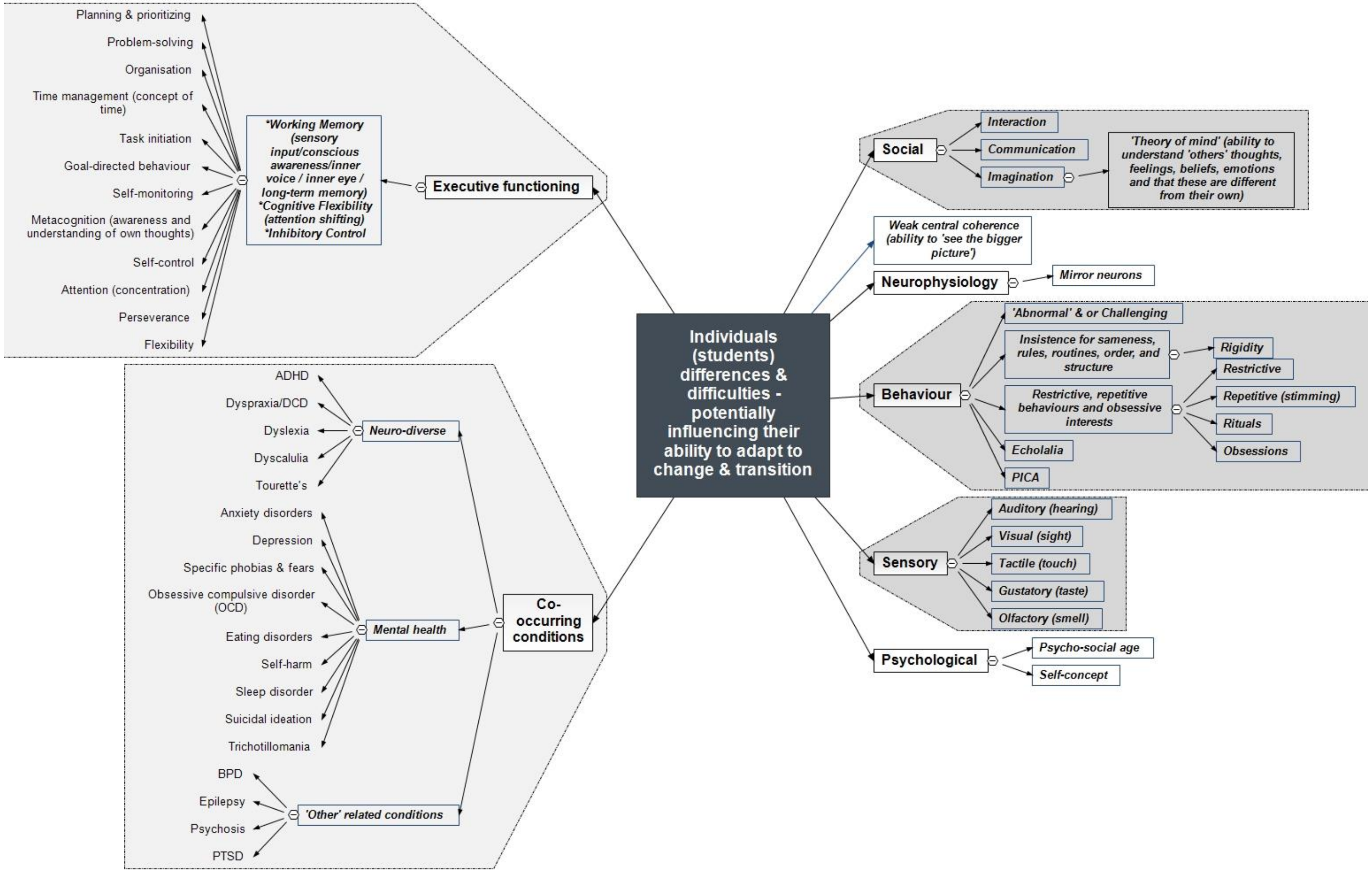


Figure 1.5: A summary of the characteristics and co-occurring conditions that can occur in individuals (students) with autism, that could potentially impact their ability to adapt to change and transition.

1.8 About this thesis

1.8.1 Research question

What are the internal-horizontal and external-vertical transitioning experiences of students with autism throughout their education journey?

1.8.2 Aim of the research

The aim of the research is to explore the internal-horizontal (day-to-day) and external-vertical (one educational phase to another) transitioning experiences of individuals (students) with autism throughout their educational journey through their own, first-person, lived experience stories. This information will be used to promote greater overall understanding of autism, positively inform, influence policy makers and practice by encouraging them to implement strategies that will reduce existing disabling barriers. It will also be used to identify ways of breaking down any societal barriers experienced by them due to their disability (disabilities), to fight discrimination, as well as to identify positive experiences and examples of good practice. Thus, it is hoped that it will improve the lives of individuals and enable them to reach their full potential.

1.8.3 Objectives of the research

- To analyse individuals' internal-horizontal transitioning experiences during each educational phase.
    - To identify their concurrent stressors (CS) and related state of health.
    - To identify concurrent stressor support (CSS) provided and needed.
- To analyse individuals external-vertical transitioning experiences moving from one educational phase to another.
    - To identify their concurrent stressors (CS) during the move from one educational phase to another and related state of health.
    - To identify concurrent stressor support (CSS) provided whilst transitioning

between educational phases and identify support needed.

- To identify what shapes individuals’ reality, self-advocacy, self-identity formation, resilience, and any disabling experiences.
- To identify each individuals core transitioning themes (CTT), sub-themes (TST) and concurrent stressor (CS) topics.
- To identify core transitioning themes (CTT), sub-themes (TST), and concurrent stressor (CS) topics, across the individual cases, and analyse in conjunction with related literature.
- Following the completion of the thesis, to use the information within to produce a guide: ‘Educational Transitions. A guide to best practice: Supporting neuro-diverse students’ transitions into a new educational phase and with their day-to-day needs’. This guide is intended for educational support providers, illustrating potential barriers, differences and difficulties facing individuals (with autism and related neuro-diverse conditions), on their educational journey, and the support needs that they might have.
- Following the completion of the thesis, to use the information within to produce resources for neuro-diverse students (their families): (1) ‘Preparing for secondary school or sixth form: Managing your transition into a new educational phase and your day-to-day needs’ and (2) ‘Preparing for university: Managing your transition into university and your day-to-day needs’.

1.8.4 Research Participants

The individuals who participated in this thesis had all progressed through education to the university level. Thus, all were considered to be ‘higher functioning’ and, under the current diagnostic frameworks explained earlier, would be considered to be “*Autism spectrum disorder level one*”[7(p52)] under DSM-V criteria or as having an ICD-11 diagnosis of “*Autism spectrum disorder without disorder of intellectual development and with mild or no impairment of functional language*”.[8(6A02.0)] Those diagnosed with autism before 2013, would have been diagnosed with Asperger’s disorder or Asperger’s syndrome[24, 47] and, thus, may still refer to themselves as having ‘Asperger’s’ or being an ‘Aspie’.

1.8.5 Research title

Key to the methodology and theoretical framework was deciding the title of the thesis, which needed to represent the research question, the intent of this written thesis, what the research wants to reflect and/or evoke, its rhetorical form, its theoretical positioning, its formatting, as well as search engine factor considerations. I (the researcher) decided upon the research title, '***Stories of students with autism***, ***their lived experiences transitioning throughout education: A narrative analysis***'. The full reasoning behind this choice of title will be addressed as the chapters evolve.

Chapter 2: Literature review

2.1 Chapter overview

Internal-horizontal transitioning and **external-vertical transitioning** experiences have been explored. Theoretical concepts of change and transition investigated namely, Schlossberg's transitioning theory, bio-ecological model, hierarchy of needs model and the four-phase adaptive cycle model. The critical literature review section evidences the experiences shared by individuals (with autism), parents, and professionals, during transitions. A multitude of influential factors appear to shape transitioning experiences. Emotional-social differences and difficulties (D&D) such as friendship, mental health (MH), bullying and discrimination, and groups. Academic D&D. Being autistic D&D, such as someone's understanding about autism, whether on the part of the individual (with autism) or others, their ability and willingness to disclose and/or ask for support, as well as the impact of co-occurring conditions. Transitioning between educational phases D&D, transition support, sensory D&D, change and uncertainty D&D, independence D&D, accommodation-campus-classes D&D, and communication D&D.

2.2 Introduction and Background

2.2.1 Literature review research question

In accordance with the overall research aim and points discussed in the introduction chapter, the role of this literature review, within the context of this PhD, is to produce a pragmatic and reliable representation of the transitioning experiences of students with autism, day-to-day and transitioning from one educational phase to another and to document any themes arising from the literature. Thus, the main aim and purpose of this standalone, comprehensive, and systematic literature review with meta-aggregation is to answer the literature review main research question: What are the transitioning experiences of students with autism? With the sub-questions exploring this from both (a) day-to-day (internal-horizontal transitioning) perspectives and (b) changing from one educational phase to another (external-vertical transitioning) perspectives. It is not the purpose of this standalone literature review to reinterpret any research data.

In the context of this thesis transition refers to the process of change that an individual goes through, moving from one experience to a new experience, which is different in some manner. As defined in Johansson,[182] the forms of transitions discussed in the context of this thesis are (1) internal-horizontal transitions, the day-to-day changes which occur during an educational phase and (2) external-vertical transitions which occur when a person moves from one phase to another e.g., primary to secondary, secondary to sixth form, sixth form to university.[182] The educational transitioning experiences of individuals are made up from multitudinal factors, and it is my (the researcher's) job to interpret and analyse these as narrative data whether; internal-horizontal transitions, or external-vertical transitions, to truly represent the individual's lived experiences in this thesis.

I will continue to use the term 'individual(s)' to refer to individual(s) or student(s) with autism in the research studies being reviewed. The term 'other(s)' will be used throughout this chapter to refer to others included in the research studies who are directly involved in the support of individuals. Thus, others could include parents, teachers, and any other support workers whose input was gathered in the course of the studies. Other key terms and synonyms used throughout this review have been summarised in table 2.1. Definitions of terms can be found in the glossary section.

2.3 Methodology and Methods

A systematic empirical literature review with meta-aggregation, developed by the Joanna Briggs Institute (JBI)[185] in 2014, was deemed (by me, the researcher) to be the most appropriate qualitative approach. This literature review used this approach as a means to synthesise evidence-based, primary qualitative research, to summarise what is currently known about the educational transitioning experiences of individuals and to use this combined information to build upon existing knowledge. Empirical qualitative literature included used methods of direct observation and/or other qualitative data methods that explored the experiences of individuals. Finally, this was sourced, whenever possible, in line with the ‘alternative hierarchy of evidence’ proposed by Noyes.[186] This hierarchy was designed to be context specific to account for evidence based views and experiences and, thus, was believed to be most applicable in answering the literature review question in the context of individuals, their views and experiences, see figure 2.1.

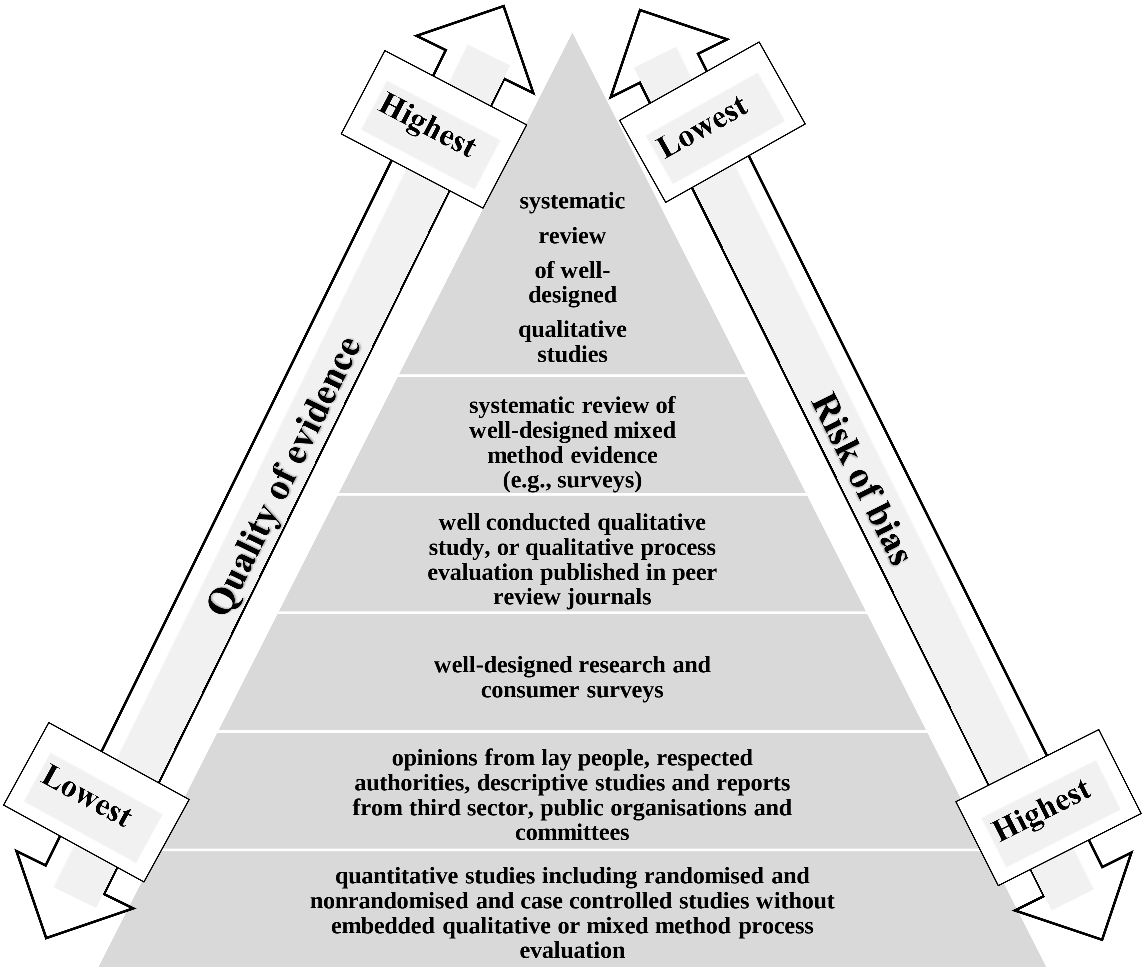


Figure 2.1: View, experiences, and hierarchy of evidence. Adapted from: Noyes[186(p530)]

2.3.1 Search strategy

2.3.1.1 Key search terms and synonyms

I (the researcher) refined the scope of the review by establishing key search terms which would enable me to source literature relating to the main concepts of the research question and sub questions. Table 2.1 demonstrates how concepts relating to the literature review questions resulted in key search terms, using Fineout-Overholt et al[187(p158)] PICO (population, issue, context, outcome) qualitative model.

Table 2.1: Identification of key terms using the PICOT.

Literature review question: What are the transitioning experiences of students with autism?				
	Population	**Issue**	**Context**	**Outcome**
PICO (qualitative) term	Autism	Transitioning	Education School College University	Experience
Alternative terms (synonyms)	• ASD • Aspergers • ‘Higher functioning’ • neurodevelopmental • neurodiverse	• change • experience	• College • University • Further Education (FE) • Higher education (HE) • Primary • Secondary • Sixth form • Student • Support • Tutoring	• Bullying • Executive function • Friendship • Loneliness

Adapted from: Fineout-Overholt et al[187(p158)]

2.3.1.2 Inclusion and exclusion criteria

JBI[185(pp26-28)] guided the inclusion and exclusion criteria in this literature review, as illustrated in table 2.2. I used inclusion criteria relating to the (1) **types of participants**, individuals (in title of advanced search), (2) **types of phenomena of interest**, transitioning (in title of advanced search) experiences throughout education, internal-horizontal transitions and external-vertical transitions, (3) **context**, individuals internal-horizontal transitioning experiences and external-vertical transitioning experiences in the context of their educational journey, (4) **types of outcomes**, individuals’ experiential accounts, as well as proxy parental, teachers, support persons, description of individuals’ experiential accounts and (5) **types of studies**, empirical qualitative literature with direct observation data and/or data that explores the experiences of individuals, this allowed for incorporation of the three highest quality levels in the Noyes[186(p530)] alternative hierarchy of evidence (figure 2.1).

Additional limits (restrictions)

Inclusion and exclusion criteria was further guided by Smart[188(p5)] with the additional limits or restrictions being put in place. Firstly, for **location**, namely UK, USA, Canada, Australia, and New Zealand. This ensured that educational experiences of individuals were aligned and papers were written in English. Secondly, the **type of resource** was limited to articles in peer-reviewed journals. In terms of quality of evidence, this allowed for incorporation of the three highest quality levels in the Noyes[186] alternative hierarchy of evidence. Finally, if the initial search results were greater than 100 articles then a **publication date** specification would be inputted as 2010 - 2020 (to current year), as illustrated in table 2.2 and if search results were still greater than 50 then additional subject inclusion and exclusion criteria would be added as illustrated in table 2.3.

Table 2.2: Inclusion and exclusion criteria.

Category	Inclusion criteria	Exclusion criteria
Types of participants	• Individuals with a medical diagnosis of autism or other alternative terms for autism (i.e., ASD, Asperger, Atypical autism)	• Individuals without a medical diagnosis of autism. • Individuals with autism and a learning disability • Kindergarten/pre-school individuals
Types of phenomenon of interest	• Transitioning throughout education; namely ○ Day-to-day or internal-horizontal transitions ○ From one educational phase to another or external-vertical transitions	• Unrelated to educational transitioning; including ○ into employment ○ into vocational work
Context	• First-hand descriptions of transitions in the mainstream educational environment	• Second-hand descriptions of transitions in the mainstream educational environment • Unrelated to transitions in the mainstream educational environment, including those relating to ○ Employment ○ Specific programme ○ Specialist schools ○ Planning
Types of outcomes	• Experiential accounts from individuals with autism • Descriptions by others of the experiences of individuals with autism; including those of ○ Parents or parental figures ○ Teachers ○ Support persons	• Experiential accounts that are unrelated to general transitioning experiences, including those relating to ○ Specific support programmes ○ Planning
Types of studies	• Systematic reviews of qualitative studies • Systematic reviews of mixed method evidence • Qualitative studies in peer review journals	• Articles that are not qualitative in nature
Location	• Worldwide	• Countries with an incomparable education system (e.g., non-European, Asian, Arabic). NB: with the exception of USA, Australia, New Zealand.
Type of resource	• Peer reviewed articles	• Not peer reviewed articles
Publication data	• 2010-2020	• If 2010- 2020 search results were still greater than 50 articles then additional related 'subject' criteria will be added e.g., students

Adapted from: JBI[185(pp26-28)], Noyes[186]and Smart[188(p5)]

Table 2.3: Additional search criteria when hits >50.

Category	Inclusion criteria	Exclusion criteria
Additional search criteria	'subject' specifications	If search criteria is over 50 then exclusion criteria will be added e.g., special education/education interventions/foreign countries/pre-school /intervention special/early intervention

2.3.1.3 Electronic database searching

Several evidence-based research (EBR**)** data bases were used to source literature. Consumer Health Database, EBSCO, Education Database, Elsevier ScienceDirect, KB + Jisc Collections Cambridge university press, KB+ JISC Collections Springer Compact, KB+ Wheel SAGE, Nursing & Allied Health Database, ProQuest Central, ProQuestion Hospital Collection, Psychology Database, PubMed Central, Research Gate, SAGE, Science Direct, SpringerLink, Social Science Database, Sociology Database and Wiley were accessed through Swansea University 'i-find'. In addition, ProQuest, SAGE, and Science direct were accessed directly through their own websites.

For all searches Boolean operators were used. For example, '*and*' was used when searching for multiple terms in the title and '*not*' was used to exclude subjects when hits were greater than 50. The standard procedure for word truncation was used when multiple word endings were likely. This ensured that all word variants were captured during a search. Search limiters of '*title*', '*any field*', '*availability*', '*resource type*', '*date*' and '*subject*', were used, as documented in tables 2.2 - 2.3, and figures 2.2 - 2.3.

The literature review took place at two separate time points. Firstly, a background literature review took place in 2017, and secondly a final literature review took place in October 2020. Due to the educational term '*transition*' being commonly used in research literature to refer to the '*transition from one educational phase to another*', rather than '*day-to-day transitions*', it was essential to do two variations of the literature search, firstly '*autism (related term) transition*' in the '*title*' of the search, figure 2.2., and secondly '*autism (related term)*' in the '*title*' of the search with '*experience*/transition**' in the '*any field*' category, figure 2.3. This aimed to source articles relating to day-to-day transitions that might have otherwise been missed. Figure 2.2 and 2.3 summarises the advanced search strategy implemented in accordance with inclusion criteria.

Title:	Asperger Transition	**Title**: College	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: School	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: Education	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: University	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
Title:	Autism Transition	**Title**: College	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: School	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: Education	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: University	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
Title:	Autistic Transition	**Title**: College	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: School	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: Education	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: University	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
Title:	High functioning Autism Transition	**Title**: College	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: School	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: Education	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: University	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
Title:	ASD Transition	**Title**: College	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: School	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: Education	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: University	**Any field**: Experience*	**Availability**: Peer reviewed	**Resource type**: articles

Figure 2.2: Advance search strategy implemented in accordance with inclusion criteria using ‘autism (related terms) transition’ in title

Title:	Asperger	**Title**: College	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: School	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: Education	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: University	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
Title:	Autism	**Title**: College	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: School	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: Education	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: University	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
Title:	Autistic	**Title**: College	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: School	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: Education	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: University	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
Title:	High functioning Autism	**Title**: College	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: School	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: Education	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: University	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
Title:	ASD	**Title**: College	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: School	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: Education	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles
		Title: University	**Any field**: Experience* / transition*	**Availability**: Peer reviewed	**Resource type**: articles

Figure 2.3: Advance search strategy implemented in accordance with inclusion criteria using ‘autism (related terms)’ in title

2.3.1.4 Selection of relevant papers

As outlined in figure 2.4, the initial search adhering to inclusion and exclusion criteria, resulted in a total of 475 hits, after duplications were removed. These results were stored in Microsoft Excel and their titles screened for eligibility by a combination of eye and using the ‘find’ function in Excel. A total of 542 articles were removed due to duplication. Further search strategies were used to eliminate papers that did not meet the inclusion criteria such as; exclusion criteria words in title and exclusion criteria terminology in the gist of the title (see appendix 2.1). The remaining 69 papers had their abstracts screened, determining if they met the inclusion criteria or should be excluded based on exclusion criteria and a further 12 were deemed inappropriate for inclusion. All systematic reviews amongst the remaining studies (n=6) had their reference lists checked and any studies where titles and abstracts met the eligibility criteria were added to the selection of papers on the excel spreadsheet (n=4). This final list of 61 articles were checked for full text availability and any papers, which were unable to be sourced, were removed (n=3). I screened the full text for 58 papers for eligibility using a check list (appendix 2.2) to ensure the papers met the inclusion and exclusion criteria. This resulted in a final number 36 papers that were deemed suitable for data extraction.

2.3.1.5 Recording results

Literature review results were recorded using PRISMA (preferred reporting items for systematic reviews and meta-analysis), through adaption of Moher et al[189(p8)] model and Page et al[190] updated guidelines, as illustrated in figure 2.4 and table 2.4.

2.3.2 Data extraction

2.3.2.1 Selection of relevant papers for data extraction

A data extraction summary sheet was used to enable me to gather relevant information that could then be critically appraised and used in the literature analysis. Table 2.4 illustrates the data extract findings for 36 studies.

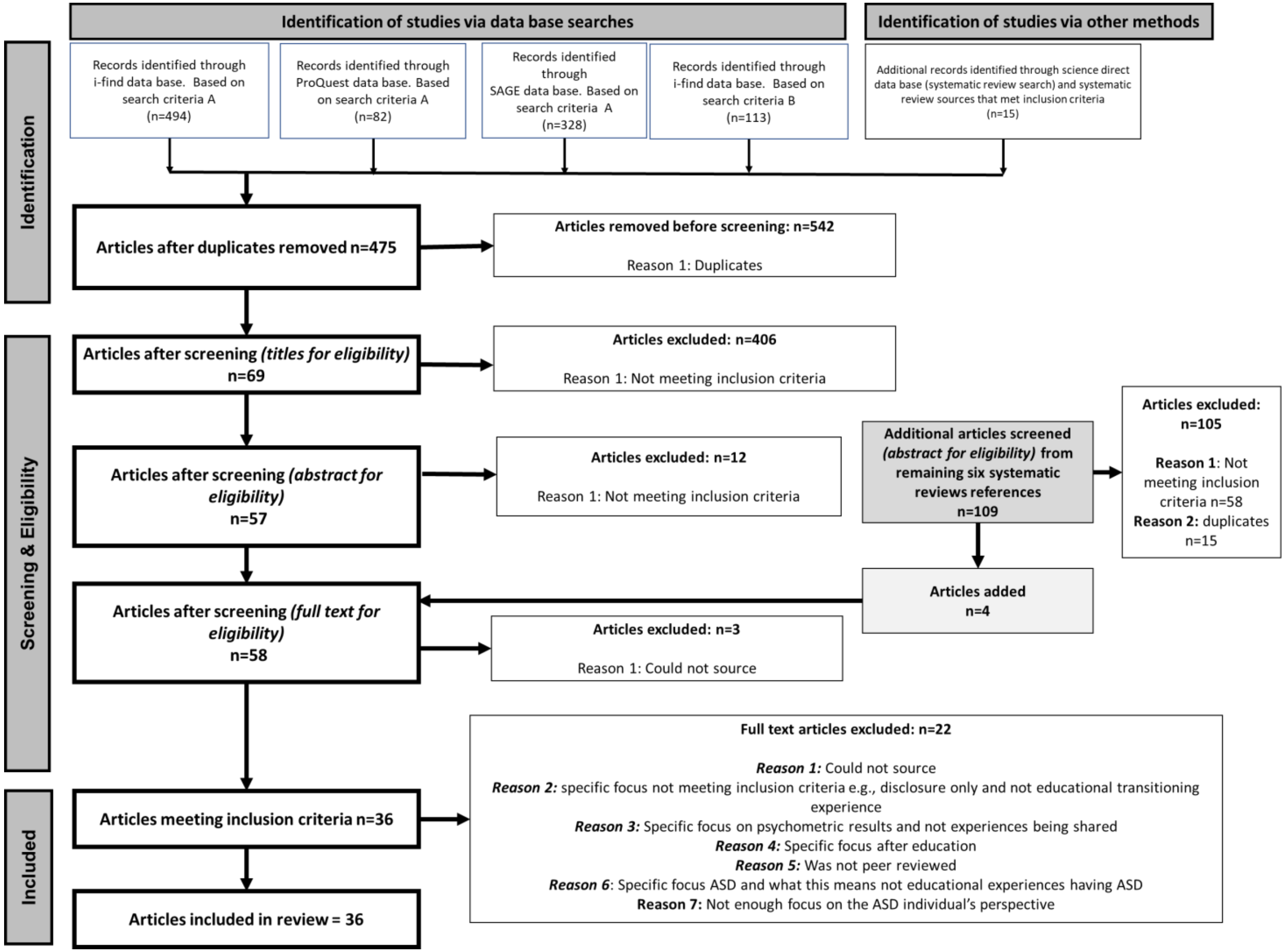


Figure 2.4: Article inclusion PRISMA flow diagram. Adapted from: Moher et al[189(p8)] model and Page et al[190] updated guidelines

Table 2.4: Data extraction summary: The educational transitioning experiences of individuals with autism (day-to-day and from one educational phase to another).

Author	**Aim**	**Participant (with ASD)**	**Participant (supporting person with ASD)**	**Method**	**Limitations ***	**Educational phase**	**Key themes**
Alverson et al[191]	Investigating the high school to college transitioning experiences of young adults diagnosed with Asperger	*n=5*	*n=22* (parent/ staff)	Phenomenological qualitative approach using individual interviews over a 6- to 12-month	Possible bias as reflecting experiences of ASD individuals diagnosed prior to 2013 when diagnostic criteria was stricter	FE/6 & HE/Uni	Communication / Emotional-social (friendship) / ‘Their autism’
Anderson et al[192] (2018)	Perspectives of university students with autism in Australia	*n=48*	n/a	Qualitative. Online survey.	Required respondents to have good computer skills to access online survey. Those struggling academically or emotionally-social may not have been in position to respond.	HE/Uni	Academic / Accommodation-campus-classes / Change & Uncertainty / Communication / Emotional-social (bullying &/or discrimination, groups, mental health) / Sensory / ‘Their’ autism (co-occurring conditions, disclosing autism) / Transition support (mentoring, support in general) / Transitioning between educational phases
Anderson et al[193] (2020)	Investigating university experience of students with ASD	*n=11*	*n=6*	Qualitative descriptive approach.	ASD diagnosis not verified. Recounting past experiences when disability services may have been different to current situation and possibly providing inaccurate data on current service provisions.	HE/Uni	Academic / Accommodation-campus-classes / Change & Uncertainty / Emotional-social (bullying & or discrimination, friendship, groups, mental health) / ‘Their’ autism (co-occurring conditions, disclosing autism / Sensory / Transition support (mentoring, study skills, support in general) / Transitioning between educational phases
Anderson et al[194] (2017)	Investigating college experience for young adult with ASD	*n=7*	*n=18*	Qualitative interviews, grounded theory approach.	ASD diagnosis unverifiable	HE/Uni	Independence / Transitioning between educational phases (from FE to HE)
Beardon et al[195]	To enable individuals with ASD to voice their opinions, highlight challenges experienced, and establish an evidence base on which to improve services	*n=238*	n/a	Qualitative questionnaires (closed and open questions).	Self-reported data and ASD diagnosis unverifiable. Complex data with the potential for multiple interpretations.	FE/6 & HE/Uni	Emotional-social (groups), ‘Their’ autism
Bolourian et al[196]	Investigating university experiences from the ASD students’ perspectives, likely factors impeding meaningful post-secondary experiences	*n=13*		Qualitative interviews, content analysis.	Data from behavioural measures were not available to enrich findings.	HE/Uni	Academic / Accommodation-campus-classes / Emotional-social (friendship / groups / mental health) / Independence / ‘Their’ autism (co-occurring conditions, disclosing autism) / Transitioning between educational phases (FE-HE)

Author	Aim	Participant (with ASD)	Participant (supporting person with ASD)	Method	Limitations *	Educational phase	Key themes
Bottema-Beutel et al[197]	Perspectives of autistic youth high school experiences, on the impacts of autism, school professionals, family members, and peers.	*n=248*	n/a	Online survey (open ended questions). Content analysis.	Self-reported data and ASD diagnosis unverifiable. Anonymous with payment incentive which might encourage misrepresentation.	S & FE/6	Academic / Emotional-social (bullying, friendship, mental health) / 'Their' autism / Transition support (mentoring, study skills, support in general)
Cage et al[198]	Examining ASD experiences at university and the reasons they dropped out.	*n=14*	n/a	Semi-structured interviews. thematic analysis.	Participants were predominantly late-diagnosed ASD, undiagnosed at the time of dropping out, likely to influence self-understanding and support provisions. Recounting past experiences prior to Equality Act 2010, when disability services may have been different to current situation possibly resulting in inaccurate data on current service provisions.	HE/Uni	Academic / Accommodation-campus-classes / Communication / Emotional-social (friendship, mental health) / Independence / Sensory / 'Their' autism /Transition support (support in general)
Cai et al[199]	Investigating educational experiences and support needs of ASD students in HE.	*n=23*	*n=15*	Semi-structured questionnaire.	(*)	FE/6 & HE/Uni	Academic / Change & uncertainty / Communication / Emotional-social (groups, mental health) / 'Their' autism (co-occurring conditions, disclosing autism) / Sensory
Camarena et al[200]	Investigation of post-secondary aspirations for adolescents with autism, obstacles and resources shaping their educational achievements.	*n=21*	*n=33*	Semi-structured interviews (closed and open ended).	Self-reported data and ASD diagnosis unverifiable.	FE/6	Academic/ Emotional-social (friendship) / 'Their' autism
Cheak-Zamora et al[201]	Exploring social, educational, and vocational needs and experiences of ASD youths and care givers.	*n=13*	*n=19*	Focus groups. Grounded theory.	Focus groups may be confusing and overwhelming for some ASD participants.	FE/6 & HE/Uni	Emotional-social (mental health)
Cremin et al[202]	Exploring parents perspective on transition to and early experience of secondary school for students with autism.	n/a	*n=8*	Qualitative exploratory descriptive method. Thematic analysis.	Self-selected group of parents. Fathers underrepresented. Not involving stakeholders.	P & S	Academic / Change & Uncertainty / Emotional-social (friendship) / Sensory / 'Their' autism / Transition support (support in general) / Transitioning between educational phases
Deacy et al[203]	Investigating best practice in relation to the planning, process and strategies that support the transition of students with ASD from primary to post-primary school.	n/a	*n=30* (SEN teachers)	Mixed methods: Online survey questionnaire (Quantitative data using SPSS).	Not involving stakeholders or individuals with ASD.	P & S	Communication / Transitioning between educational phases

Author	Aim	Participant (with ASD)	Participant (supporting person with ASD)	Method	Limitations *	Educational phase	Key themes
Dillon et al[204] (2012)	Investigating parental perspective of the transfer from mainstream primary to secondary school for children with autism.	n/a	*n=15*	Mixed methods: Semi-structured questionnaires / followed by in depth interviews. Pre-transition: focus groups and in-depth interviews. Post-transition: retrospective perceptions. Grounded theory.	No involvement of individual with ASD.	P & S	Academic / Accommodation-campus-classes / Change & Uncertainty / Communication / Emotional-social (bullying &or discrimination, friendship, mental health) / Sensory / 'Their' autism / Transition support (mentoring, study skills, support in general) / Transitioning between educational phases
Dillon et al[205] (2016)	Investigating school experiences of ASD children compared with the typically developing school children.	*n=14* (n=14 without ASD)	n/a	Mixed methods: Self-reported questionnaires and semi-structured interviews.	Self-reported data and ASD diagnosis unverifiable.	S	Academic / Emotional-social (friendship, groups) / 'Their' autism / Transition support (support in general)
Dixon et al[206]	Investigating the perceptions of key stakeholders in the transition of two students with AS into high schools.	*n=2*	*n=6*	Case study. Semi-structured interviews. Thematic analysis.	Lack of engagement and lack of rich responses from 1 ASD participant.	S & FE/6	Academic / Emotional-social (groups) / 'Their' autism (disclosing autism) / Transition support (support in general)
Foulder-Hughes et al[207]	Investigating how children with ASD and/or DCD felt about the transition to secondary school from primary.	*n=5* (n=1 DCD only)	n/a	Face to face semi-structured interviews. Thematic analysis.	Not purely focused on ASD, inclusion of DCD.	P & S	Emotional-social (co-occurring conditions, mental health)
Gelbar et al[208]	Surveying experiences of individuals with ASD at college or who had previously attended.	*n=35*	n/a	Online survey.	Self-reported data and ASD diagnosis unverifiable.	FE/6 & HE/Uni	Academic / Emotional-social (bullying, friendship, mental health) / 'Their' autism
Gurbuz et al[209]	To understand the social and academic experiences of autistic university students.	*n=26* (n=158 non-ASD)	n/a	Online questionnaire. Thematic analysis.	Self-reported data and ASD diagnosis unverifiable.	HE/ Uni	Academic / Change & Uncertainty / Emotional-social (friendship, mental health) / Sensory / 'Their' autism / Transition support (mentoring, peer support, study skills)
Hastwell et al[210] (2013)	As part of this project: Longitudinal study to investigate the experiences of ASD university students.	*n=28*	n/a	Longitudinal study. Thematic analysis.	(*)	HE/ Uni	Academic / Accommodation-campus-class / Emotional-social (mental health) / Sensory / 'Their' autism / Transition support (mentoring, peer support, study skills, support in general)

Author	Aim	Participant (with ASD)	Participant (supporting person with ASD)	Method	Limitations *	Educational phase	Key themes
Hastwell et al[211] (2012)	Investigating what would improve AS students university experience and increase their life chances.	*n=28*	n/a	Part of longitudinal study. Focus groups, one to one interviews, email.	(*)	HE/ Uni	Academic / Emotional-social (bullying and/or discrimination) / Sensory
Hatfield et al[212]	Exploring predisposing, reinforcing, and enabling factors related to the transition planning processes for adolescents with autism.	*n=26*	*n=136 (n=83 parents/ n=53 professionals)*	Online questionnaire (closed and open-ended questions).	Self-reported data and ASD diagnosis unverifiable. Higher socio-economic backgrounds. Questionnaire not tested previously for validity and reliability.	FE/6 & HE/Uni	Transitioning between educational phases
Hillier et al[213]	To evaluate the effectiveness of a support group model for university students in improving psychological and functional outcomes.	*n=25*	n/a	Focus group. Self-reported questionnaires.	Focus groups may be confusing and overwhelming for some ASD participants and unclear who final data came from.	HE/ Uni	Academic / Emotional-social (mental health) / Independence
Hoy et al[214]	Investigating the experiences of the primary to secondary school transition of children with ASD, from multiple stakeholders.	*n=5*	*n=10* (n=6 teachers/ n=4 parents)	Semi-structured interview. Case study.	(*)	P & S	Transition support (support in general) / Transitioning between educational phases
Humphrey et al[215]	Exploring how pupils with AS make sense of their educational experiences.	*n=20*	n/a	Semi-structured interviews, pupil diaries & drawings.	(*)	S	Change & Uncertainty / Emotional-social (bullying &or discrimination, friendship, mental health)/ 'Their' autism (disclosing autism) / Transition support (support in general)
Lambe et al[216]	Investigating the views of students with autism preparing to start uni. Hopes, Worries, Concerns.	*n=25*	n/a	Focus groups. Thematic analysis.	Focus groups may be confusing and overwhelming for some ASD participants and asking students to project into the future may be difficult due to social imagination deficits.	HE/ Uni	Academic / Emotional-social (bullying, co-occurring conditions, mental health) / Independence
Makin et al[217]	Examining the factors that influence a successful school transition for autistic children in one local education authority in England.	*n=15*	*n=32 (n=14 parents/ n=18 teachers)*	Mixed methods: Psychometric questionnaires (quantitative). Semi-structured interviews (qualitative).	(*)	P & S	Academic / Emotional-social (bullying, mental health) / Change and uncertainty / Sensory / 'Their' autism / Transitioning between educational phases

Author	Aim	Participant (with ASD)	Participant (supporting person with ASD)	Method	Limitations *	Educational phase	Key themes
Mitchell et al[218]	Investigating support needs of young people with ASD prior to starting college.	*n=18*	n/a	Semi-structured interviews.	Self-reported data and ASD diagnosis unverifiable, opinions regarding the type of support they valued and who provided support may differ, especially the role of parents, with wider population.	FE/6 & HE/Uni	Transitioning between educational phases
Peters et al[219]	Exploring experiences of the transition to secondary school for students with AS/HFA from the parental perspective.	n/a	*n=17*	Mixed methods. Online questionnaire (closed and open ended).	Self-reported data and ASD diagnosis unverifiable, access to a computer and the internet may have limited participation.	P & S	Academic / Change & uncertainty / Emotional-social (groups, mental health) / Transitioning between educational phases
Sosnowy et al[220]	Investigating key areas of independent living, post-secondary education, and employment for individuals with ASD.	*n=18*	*n=16*	Interview survey.	(*)	FE/6 & HE/Uni	Academic / Independence / 'Their' autism (co-occurring conditions, disclosing autism)
Stoner et al[221]	Investigating perspectives and concerns of parents of young children with ASD related to transitions.	n/a	*n=8*	Interviews and observations. Cross-case analysis.	Parents taking part in study were potentially more action orientated or problem-focused, not representative of population.	P	Transitioning between educational phases
Tobias[222]	Investigating the challenges and support needs of secondary school children with autism.	*n=10*	*n=5*	Focus groups.	Focus groups may be confusing and overwhelming for some ASD participants.	P & S	Academic / Sensory / 'Their' autism / Transition support (mentoring, peer support, study skills, support in general) / Transitioning between educational phases
Van Hees et al[223] (2014)	Investigating the challenges and support needs of higher education children with autism.	*n=23*	n/a	Semi-structured interviews. Grounded theory.	Potential selection bias due to students who attended regular interviews, actively involved in transition planning, being interviewed, which might not represent wider population.	FE/6 & HE/Uni	Change and uncertainty / Emotional-social (mental health) / 'Their' autism (disclosing autism)
Van Hees et al[224] (2018)	Examining how senior students and first-year college students with autism spectrum disorder, their mothers and fathers navigate the higher education transition, and how this context impacts on dynamics in the parent–child relationships.	*n=34*	*n=60*	Semi-structured interviews. Grounded theory.	Potential familiar bias - those involved had a 'warm' relationship.	FE/6 & HE/Uni	Academic / Change & Uncertainty / Emotional-social (bullying and/or discrimination,, friendship) / Independence

Author	Aim	Participant (with ASD)	Participant (supporting person with ASD)	Method	Limitations *	Educational phase	Key themes
Vincent[225]	Identifying the specific experiences of young autistic adults making this transition.	*n=21*	n/a	Semi-structured interviews.	Self-reported data and ASD diagnosis unverifiable.	HE/ Uni	Emotional-social (mental health) / Transitioning between educational phases
Wiorkowski[226]	Investigating the experience of individuals with autism spectrum disorders who have experienced the higher education system.	*n=12*	n/a	Face to face interviews. Data analysed using heuristic methodology of Dr. Clark Moustakas (1990).	May have excluded less sociable ASD individuals.	HE/ Uni	Academic / Change & uncertainty / Emotional-social (bullying &or discrimination, friendship, groups, mental health) / Independence / 'Their' autism (disclosing autism) / Transition support (mentoring, peer support, study skills)

Adapted from**:** Aveyard et al.[227]

*General limitations which apply to all quantitative studies includes: Data is not generalisable. Potential selection bias. Likely to not represent the wider population, gender differences, different levels of autism, differency between countries/locality. Likely to not be transferable to another education system. The majority of studies have a small number participants which might restrict granuality of data and not reflect the wider population. P=primary, S=secondary, FE=further education, 6=sixth form, HE=higher education, Uni=university

2.3.3 Critical appraisal

I assessed the literature quality (credibility, confirmability, dependability, transferability, and plausibility) using the critical appraisal qualitative checklist from Joanna Briggs Institute[228] (2020) and Lockwood et al[229] research synthesis guidance, located in appendix 2.3.

2.3.4 Analysis and synthesis

I analysed and synthesised the literature through meta-aggregation. This involved thematically bringing together literature data, into generalised statements, recommendations for action in this research area and guidance for future practice. Meta-aggregation synthesis guidance was sought from Hannes et al[230] and Aveyard et al[227] with me clearly defining concepts, linking themes between papers and defining pragmatic lines of action leading to recommendations for future practice.

Thirty-six research articles were analysed and synthesised using the following steps; (1) identifying and coding the paper's main findings or results, (2) developing themes, by tabulating codes into themes, (3) naming themes, (4) comparing themes, assessing whether the name given to a theme was appropriate and whether codes fit themes, (5) considering the quality of papers on overall theme, (6) considering the consistency of data overall, and (7) justifying how themes were interpreted and data included in results.[227] Figure 2.5 illustrates the themes, sub-themes, and number of studies relating to each theme. A more detailed description of this can be found in appendix 2.4, tables A-J, which features the literature synthesis into transitioning themes, subthemes, and the study participants who shared their experiences has been specified for clarity (e.g., individual, or other).

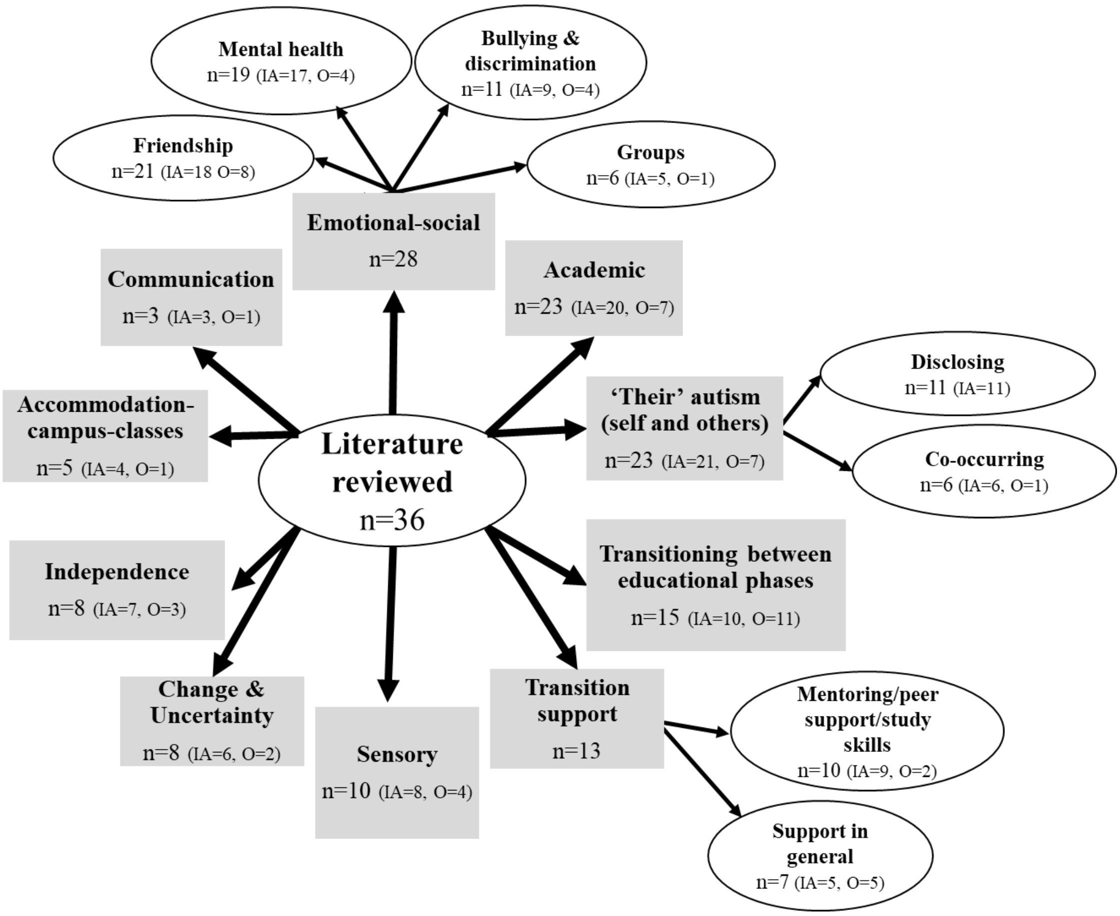


Figure 2.5: Overview themes and sub-themes within literature reviewed. Where n is the total number of studies included in the theme or subtheme. These studies are also split into IA (number of studies that involve first person accounts from individuals with autism) and O (number of studies that involve the accounts collected from other individuals involved in the support of an individual with autism e.g., parents, teachers, support workers).

2.4 Results

This meta-aggregation literature review explored the educational transitioning experiences of individuals, day-to-day (internal-horizontal) and transitioning from one educational phase to another (external-vertical). The major findings of this review highlight the limited studies that document individuals' experiences of said transitions. Unsurprisingly, as it is the core attribute of autism, the predominant theme in this review was emotional-social challenges and experiences. Although many themes overlapped, other themes relating to individuals' experiences that followed, in order of dominancy in the literature review, were (1) emotional-social (n=28), (2) academic (n=23), (3) 'their' autism (n=23), (4) transitioning between educational phases (n=15), (5) transition support (n=13), (6) sensory (n=10), (7) change and uncertainty (n=8) (8) independence (n=8), (9) accommodations-campus-classes (n=5) and (10) communication (n=3). Each theme included first-person accounts from individuals with autism (IA), and others (O), including their parent(s) and/or support persons, as illustrated in figure 2.5.

2.4.1 Emotional-social

The majority of studies, twenty-eight in total, referred to emotional-social experiences,[191-193, 195-202, 204-211, 215-217, 219, 220, 223-226] with emotional-social skill deficits commonly presenting for individuals.[193] This theme was broken down into four sub-themes namely (1) friendship (n=21), (2) mental health (n=19), (3) bullying and/or discrimination (n=11), and (4) groups (n=8). As illustrated in figure 2.5 and detailed further in appendix 2.4, table A.

2.4.1.1 Friendship

Out of twenty-one studies, eighteen studies reflected the direct experiences of individuals[191-193, 197-200, 205, 206, 208, 209, 215-217, 220, 223, 224, 226] and eight studies represented others' views of individuals' experiences.[191, 202, 204, 206, 217, 219, 220, 224]

Forming friendships appeared to be difficult, exhausting and stressful for most individuals.[209, 219] Friendships were often stated as being non-reciprocal, particularly in their earlier years, and tended to be limited in number.[217] Many individuals said that it was something they desired, according to parents in Cremin et al[202] and worried about, particularly when transitioning from one phase to another, as mentioned by individuals in Lambe et al[216] and Gelbar et al.[208] Individuals blamed their difficulties around forming friendships on their lack of social skills,[191, 208] tendency for social avoidance,[216] their need to socialise in a quieter space[208] and them having a preference for socialising virtually.[191] They also stated how they often felt pressurized to mask their autism in order to feel like they fitted in.[193, 198, 217] Individuals shared how they sought like-minded friendships,[196] with people who shared similar interests to them, and this was something many optimistically hoped for at university, but rarely appeared to achieve.[198, 200, 220] However, it should be noted that, some did describe their university peers as more accepting, according to individuals in Anderson et al[192] and parents in Dillon et al.[204] They spoke about forming friendships through special interest groups.[193, 204, 224] Whilst some felt they benefitted from structured socialising in university (e.g., during lectures),[216] many still struggled with unstructured socialisation (e.g., in a nightclub).[216, 217]

2.4.1.2 Mental health

Out of nineteen studies, seventeen studies reflected the direct experiences of individuals[192, 193, 196-199, 201, 207-210, 215-217, 223, 225, 226] and four studies represented others' views of individuals' experiences.[201, 204, 217, 219]

Mental health (MH) related conditions and symptomology appeared frequently in the literature as impacting individuals day-to-day functioning which included the generation of worry, fear, stress, anxiety, depression, suicidal ideation, and post-traumatic stress disorder (PTSD) symptoms.[192, 196-198, 215, 225] The triggers for such conditions were numerous and wide ranging, often seen in external-vertical transitions into a new educational phase, particularly prevalent during the primary to secondary transition[204, 217, 219] as well as internal-horizontal day-to-day transitions[199, 207, 219] e.g., change of teacher. Some individuals blamed their autistic characteristics as the cause for their MH difficulties. Such characteristics included difficulties in coping with change,[193, 199, 209, 223] support needs learning life skills (advocacy, independent living, social),[191, 193, 194, 196, 198, 216, 218, 220] executive functioning (EF) difficulties,[199, 211, 213, 223] feelings of social isolation,[217] obsessive interests,[210] perfectionism,[193] procrastination[193] and feelings of social pressure to fit in.[216, 217, 223] Many blamed their current MH issues on previous negative school experiences,[196, 216, 217] particularly bullying and victimisation[211] where they felt peers often took advantage of their vulnerability[217] and exploited their social naivety.[215]

2.4.1.3 Bullying

Out of eleven studies, nine studies reflected the direct experiences of individuals[193, 197, 208, 211, 215-217, 224, 226] and four studies represented others' views of individuals' experiences.[204, 217, 219, 224]

Unstructured social times, when staff were not around, appeared to result in a lot of mental distress for individuals. This was either because bullying physically took place during this time or it triggered memories of bullying which occurred previously.[216, 217] Individuals also shared how they felt they were discriminated against by peers, teachers, lecturers, because of having a 'hidden' disability that was not considered as being serious.[198, 226] On a positive note, some saw their transition from further education (FE) to higher education (HE) as an opportunity to form friendships and a time when the bullying would stop[224] and although many individuals saw improvements, this was not the case for all.[208]

2.4.1.4 Groups

Out of six studies, five studies reflected the direct experiences of individuals[192, 193, 195, 196, 205] and one study represented others' views of individuals' experiences.[219]

Many individuals said that they found being with groups of peers challenging and stressful,[193, 195] with the majority of individuals stating that they avoided social groups altogether, according to parents in Peters et al.[219] However, a minority of individuals shared that they enjoyed academic groups[205] or specific groups and clubs.[192]

2.4.2 Academic

The majority of the literature reviewed, twenty-three studies, detailed individuals academic experiences,[192, 193, 196, 198-200, 202, 204-206, 208-211, 213, 216, 217, 219, 220, 222-224, 226] twenty studies reflected the direct experiences of individuals[192, 193, 196, 198-200, 205, 206, 208-211, 213, 216, 217, 220, 222-224, 226] and seven studies[202, 204, 206, 217, 219, 220, 222] represented others' views of individuals' experiences. As illustrated in figure 2.5 and detailed further in appendix 2.4, table B.

Executive functioning (EF) deficits appeared to impact all aspects of individuals' academic and social life.[199, 211, 216, 223] They spoke about difficulties associated with their academic independence,[213, 219] ability to focus,[208] distractibility,[199] ability to follow instructions[219] (particularly when given orally),[206] organisation[199, 200, 206, 217, 219, 220] and time management.[196, 202, 208, 223] The academic curriculum challenged many, particularly with the advancement in academic demands as they progressed through the phases.[210] Individuals outlined difficulties with academic assessments and deadlines,[196] lack of clear instructions,[209] when feedback was abstract or unclear,[198, 209] where there was lack of simplification,[205] where there was an expectation they answered questions in class,[192] with group work,[193] when there were sensory distractions[226] and when they felt there was no time for them to intensely focus on their specialist interest.[210] University appeared to be an educational phase when they could specialise in the subjects that interested them, generating excitement through being taught by people they saw as experts in the field.[216, 226] Although it was noted that a preoccupation with one particular subject was sometimes detrimental to other subjects and had the potential to result in the individual exhausting themselves.[209]

Literature evidenced how individuals appeared to be most academically challenged during the secondary school phase, according to parents in Peters et al.[219] The reasons for this included teachers not adapting their teaching style, or support, to meet their needs and teaching at too fast a pace.[204, 205, 217] However, it is worth noting that some did state that they found the more formal secondary environment and teaching style better when compared with their primary phase, according to parents in Dillon et al.[204] On joining the secondary phase, some believed that they were behind academically, lacking the foundations of English, mathematics, and science and this, they said, was due to difficulties experienced in primary school.[226] Fine-motor skill challenges occurred for some, as noted by individual in Cai et al[199] and according to parents in Cremin et al,[199, 202] which made it difficult for them to write at speed, take notes, write legibly and, thus they felt their efforts did not reflect their true academic ability.[199] Homework was presented in the literature as challenging for the majority, who struggled with the invasion of schoolwork into their home environment, according to parents in Dillon et al[204] and individuals in Dillon et al.[205] Those who did homework required additional support[205] and some mentioned that it exceeded their independent academic abilities.[217]

It was unclear in the literature whether all individuals were offered and received academic support, particularly in secondary school, with some saying they were offered it but refused to accept it because they didn’t want to be treated differently to their peers, to standout or to receive any special treatment.[196] In university timely, flexible, support was expressed as important.[199] The type of support varied amongst individuals but often included being given extra time in assessments,[199] use of note takers, access to IT equipment and software, alternative assessments to exams[200] and, for some, reducing their course from full time to part time.[193] Without such support it was noted that individuals experienced significant anxiety and stress.[198]

2.4.3 ‘Their’ autism

The majority of the literature reviewed, twenty-three studies, discussed individuals’ experiences of their autism.[191-193, 195-200, 202, 204-206, 208-210, 215-217, 220, 222, 223, 226] Twenty-one of these studies reflected the direct experiences of individuals[191-193, 195-200, 205, 206, 208-210, 215-217, 220, 222, 223, 226] and seven studies represented others’ views of individuals’ experiences.[191, 202, 204, 206, 217, 220, 222] This theme was further broken down into two additional sub-themes namely (1) disclosing autism and asking for support (n=11) and (2) co-occurring conditions (n=6). As illustrated in figure 2.5 and detailed further in appendix 2.4, table C.

Findings from the majority of studies evidenced individuals’ experiences of their autism as having co-occurring conditions (ADHD, dyspraxia, dyslexia, OCD, mental health disorders) and they discussed their experiences disclosing their autism. Many individuals shared negative experiences that resulted from others lacking autistic understanding,[195, 198, 204] having a stereotypical approach to autism,[210] stigmatising (fear of[192]) and/or patronising them.[209] Some shared that they wished, and were happier when, others had more of a person-centred empathetic approach[199] that supported their academic and social needs and was accepting and understanding of their unique differences.[210] Individuals also spoke about their difficulties socially interacting and communicating[195] which resulted in them being labelled and left out by peers.[197] They often referred to themselves in a derogatory manner (e.g., using terms such as ‘freak’, ‘having a bad brain’, ‘mentally disabled’, ‘nerd’, ‘not normal’, ‘weird’) which some researchers state is shaped by the reactions of others to them.[215] For many this resulted in them masking their autism in an attempt to fit in with peers, which proved exhausting,[193, 223] with many bullied because of their differences.[217] Although in the minority, some individuals in the literature reviewed did express a positive self-perception of their autism.[215]

Some studies demonstrated that individuals only received support in education when stress triggers resulted in them presenting with challenging behaviour, which appeared to worsen during puberty, according to parents in Cremin et al.[202] These behaviours were often termed ‘unacceptable’ rather than considering, that they resulted from autistic behaviour triggers,[199] that staff needed to modify their expectations and provide proactive support to manage these.[217, 222] The studies that related to university individuals[208-213, 216, 218, 220, 223-226] demonstrated that some individuals received their diagnosis after the primary school phase,[204] later in life,[198] or after dropping out of, this phase.[210] They felt that reasons for this late diagnosis were the result of barriers in the assessment process, such as male orientated assessment tools.[198] However, there were cases of individuals who had been assessed and hence could access support but chose not to as they didn’t want to, in their words, ‘stand out’, according to parents in Cremin et al.[202]

The majority of individuals were aware of their diagnosis but many were unwilling,[206] expressed doubts,[223] were fearful,[192, 196] to disclose their autism when starting a new educational phase. They stated that they wanted to be considered ‘normal’, treated ‘normally’, to not be stigmatised, to not stand out from their peers and to not have people feeling sorry for them.[200, 215] When disclosure did happen, it tended to be because caregivers did this or persuaded the individual to do this for support reasons[199, 206] and those that did disclose expressed positive results.[196] The majority of individuals who did not disclose prior to starting university, expressed the belief they either did not deserve the support, did not need the support or were not disabled enough to warrant it.[198] However, many ended up disclosing when their symptoms worsened and they realised support accommodations were needed.[192] For some, support was put in place but not accessed by the individual as they felt it was troublesome having to use note-takers or take exams in different rooms to their peers.[226] For many who did disclose, they were still uncomfortable disclosing to peers outside of the university campus.[208] Some individuals in Anderson et al[193] appeared to lack knowledge about university support services and/or have the advocacy skills to be able to access support, whilst others refused support due to them not having an official diagnosis, according to parents in Dillon et al.[204] For those that did choose to access support, some spoke of significant delays getting support put in place, as was the case for individuals in Anderson et al[192] and Wiorkowski.[226]

2.4.4 Transitioning between educational phases

Approximately half of the literature reviewed, fifteen studies related to the experiences of individuals transitioning from one educational phase to another (i.e., external-vertical transitions) and the team of individuals involved in supporting them.[192-194, 196, 202-204, 212, 214, 217-219, 221, 222, 225] Ten studies reflected the direct experiences of individuals[192-194, 196, 212, 214, 217, 218, 222, 225] and eleven studies represented others' views of individuals' experiences.[194, 202-204, 212, 214, 217-219, 221, 222] As illustrated in figure 2.5 and detailed further in appendix 2.4, table D.

The majority of primary individuals appeared apprehensive about their move to secondary due to loss of familiarity, moving to a bigger campus, having to communicate with multiple teachers and emotional-social worries about making new friends.[217] Past negative primary experiences appeared to trigger less optimism and negative feelings about this transition, according to parents in Dillon et al.[204] Transition planning and support took several forms such as opportunities to meet peers and key staff, tours of the school, receiving visual information about the school and having an IEP (Individual Education Plan) that accompanied them to the school.[214] The majority of individuals stated that they knew about and were involved in their transition plan.[203] Once in secondary school, the key to success appeared to be a positive relationship between the individual and staff member(s), as well as keeping regular communications between home and school, according to parents in Cremin et al.[202] For the minority, minimal or ineffective transitioning support took place, resulting in heightened levels of anxiety, according to parents in Peters et al.[219] Transitioning from secondary to sixth form (further education) appeared to be uncoordinated and an overall negative experience for the majority of individuals.[212] The majority of individuals in Anderson[192] stated that they received sixth form (further education) to university (higher education) transitioning support. Support generally took the form of help with administrative tasks, opportunities for university visits and/or orientation events, with parents still playing a significant role in this process.[218]

2.4.5 Transition support

Thirteen studies explored day-to-day transition support.[192, 193, 197, 198, 202, 204-206, 209, 210, 214, 222, 226] This theme was broken down into two sub-themes namely (1) mentoring, peer support, study skills (n=10) and (2) support in general (n=7). As illustrated in figure 2.5 and detailed further in appendix 2.4, table E.

It was clear throughout the literature that internal-horizontal or day-to-day transition support was crucial for individuals.[199, 207, 219] This support commonly included study skills support,[197, 205] mentoring,[192, 222, 226] peer support[193, 204, 210] and, sometimes, other types of alternative measures such as access to sensory free spaces, activity groups, therapy groups and life skills training.[194, 220] Study skill support was common throughout primary and secondary phases[197, 204, 222] and individuals tended to receive this support through a teaching assistant which they stated was helpful.[197, 205] Assistants aided the individual in a number of ways such as breaking work down into smaller chunks, visualizing learning, discussing academic learning and helping them to prepare for lessons.[197] They were also there to listen and it was often felt that they understood the individual’s unique needs.[205] Peer support was mentioned as an important form of support particularly in the secondary phase, according to parents in Dillon et al.[204] University individuals, however, expressed that when peer support took the form of notetaking in lectures it was not appropriate.[198] Specialist autism mentoring did not appear in the literature referring to pre-university phases. In the university phase, those that did have autism mentors, were positive about the person-centred experience and felt it helped them academically and socially.[193, 210, 226]

As discussed earlier, other disability support services were also available to individuals in their university phase, these included reasonable adjustments both in-class and for exams. Regardless of the phase, individuals that did not have or were not accessing support struggled and often disengaged academically and/or socially.[198] For those that engaged with support it appeared to help them manage their challenges, particularly when the support was person-centred.[192, 222] In the compulsory education phases, parents expressed the importance of them being able to address their child’s support needs with their school through an open-door approach.[214] This proactive method was, they felt, a good way to avoid behavioural escalations and reduced their child's overall anxiety. However, ensuring this information was disseminated to all teaching-staff involved in their support appeared to be key, as challenges sometimes arose with individuals who had multiple staff working with them, according to parents in Cremin et al.[202]

Individuals in Dixon et al[206] addressed other internal-horizontal transitioning support needs that they had such as support moving between classrooms, during free periods, and with organisational skills.

2.4.6 Sensory

Ten studies discussed sensory experiences,[192, 193, 198, 199, 202, 204, 209, 210, 217, 222] eight studies reflected the direct experiences of individuals[192, 193, 198, 199, 209, 210, 217, 222] and four studies represented others' views of individuals' experiences.[202, 204, 217, 222] As illustrated in figure 2.5 and detailed further in appendix 2.4, table F.

Sensory over and under sensitivity was common for individuals in the literature reviewed.[202-204, 214, 217, 219, 221, 222] This often related to sensory overload in their educational setting[193, 204, 217] and impacted negatively on an individual's academic performance and their ability to cope.[192, 193, 198] In one case an individual needed to change schools because of these difficulties, according to parents in Cremin et al.[202] For some, challenging behaviours sometimes resulted from sensory stimulations.[199] For these individuals, sensory free areas were seen as being an important place an individual could go, a place of safety, when they felt overwhelmed.[222] University had many elements, such as social events, pubs, clubs, that resulted in sensory challenges.[210] Lecture theatres could also sometimes cause auditory issues for individuals, making it difficult for them to process what the lecturer was saying.[209] In these cases individuals benefitted from having lecture transcription as a support measure.[193]

2.4.7 Change and uncertainty

In this literature review eight studies related specifically to change and uncertainty experiences,[193, 199, 204, 209, 215, 219, 224, 226] six reflected the direct experiences of individuals[193, 199, 209, 215, 224, 226] and two studies represented others' views of individuals' experiences.[204, 219] As illustrated in figure 2.5 and detailed further in appendix 2.4, table G.

Change and uncertainty challenges were common for the majority of individuals in the literature reviewed[193, 199, 204, 209, 215, 219, 224, 226] and was seen as a trigger for elevated levels of stress.[199, 204, 207, 208, 217, 219, 225] This was due to an individual's need for predictability, routine and structure in their day-to-day transitions.[215, 219, 224] Examples of such challenges included changes of rooms, change of teachers and social interaction changes, according to parents in Dillon et al.[204] Some individuals even stated that the lack of academic structure at university made this the most challenging phase.[199] However, these individuals also stated that once support was implemented things improved. It should be noted that there are also positives associated with change, with one study emphasising its importance in bringing about personal growth and strength in said individuals.[226]

2.4.8 Independence

Eight studies explored experiences relating to independence,[194, 196, 198, 213, 216, 219, 224, 226] seven studies reflected the direct experiences of individuals[194, 196, 198, 213, 216, 224, 226] and three studies represented others' views of individuals' experiences.[194, 219, 224] As illustrated in figure 2.5 and detailed further in appendix 2.4, table H.

As would be expected, independence challenges became more demanding with age and were sometimes seen to overwhelm individuals during their university phase.[198] Pre-university individuals expressed their desire for autonomy and independence,[224] although many still wanted parental support to continue.[224] In terms of support measures, for some, independent living skills were taught prior to starting university.[196, 213, 216]

2.4.9 Accommodation-campus-classes

Out of five studies related to accommodation-campus-classes experiences,[193, 196, 198, 204, 210] four studies reflected the direct experiences of individuals[193, 196, 198, 210] and one study represented others' views of individuals' experiences.[204] As illustrated in figure 2.5 and detailed further in appendix 2.4, table I.

In university, the larger size of academic campus was noted as being stressful for individuals as well as larger numbers of students in lecture theatres and other classes.[198] From the literature reviewed it appeared as though less than half of the university individuals lived away from home.[193, 196, 210] Those who lived on campus expressed that this was stressful and they spoke of the need for person-centred support during and after their move.[196] However, combining living at home with university-life was not without it stresses and many that chose to live at home noted the logistical stresses of the daily commute.[196]

2.4.10 Communication

Three studies referred directly to communication experiences,[191, 198, 199] however, it is important to note that communication was discussed in the context of other themes, three studies reflected the direct experiences of individuals[191, 198, 199] and one study represented others' views of individuals' experiences.[191] As illustrated in figure 2.5 and detailed further in appendix 2.4, table J.

Stressful specific communication experiences shared in the context of this review were difficulties that resulted in individuals taking what teachers said literally,[191] which led to misunderstandings and the negative consequences of academic work being completed incorrectly.[199] Some individuals spoke of how their negative experiences resulted in them avoiding oral communication wherever possible and a preference to converse via emails and virtual messaging.[191] Others felt that they missed out, because they were not part of the day-to-day communication chains or groups that their peers had.[198]

2.5 Strengths and limitations of literature review

This literature review has demonstrated the following strengths. (1) It has included studies which represented (i) first-person accounts from individuals, (ii) accounts from others, namely parents and/or staff, to fill in any gaps in information surrounding individuals' experiences and support episodic memory difficulties which are particularly relevant during the earlier educational years. (2) It purposefully focused on empirical qualitative literature, sourced in line with the Noyes' alternative hierarchy of evidence,[186] including studies that used methods of direct observation and/or data methods that explored the educational experiences of individuals, studies related to transitioning experiences, either between phases (external-vertical transitions) and/or 'day-to-day' (internal-horizontal transitions). (3) It used the PICOT qualitative model search strategy,[187] and its meta-aggregation inclusion and exclusion criteria was guided by JBI[185, 186] and Smart[188(p5)]. Boolean operators, truncation, and multiple reviews of literature in 2017 and 2020, were all implemented to ensure maximum relevant literature was identified. (4) It tracked and recorded its results using a data extraction summary sheet[227] that was in-line with PRISMA.[189, 190] Results were critically appraised and synthesized for quality through the JBI critical appraisal checklist[228] and Lockwood et al[229] research synthesis guidance. (5) The meta-aggregation synthesis approach resulted in defined themes (sub-themes), concepts, which could be compared across studies, and that could produce defined pragmatic lines of action which lead to recommendations for future practice.[227, 230]

Limitations of this meta-aggregation literature review stem from my (the researcher's) subjectively deciding what the aggregate themes, sub-themes and the usable findings are. Readers of this synthesis may have a different perspective about the findings and their relevance in terms of future research and practice. Limitations in relation to the studies included in this review must also be considered. (1) Studies may not reflect the wider autistic population due to (i) potential selection bias, (ii) studies only including individuals with ability to take part (e.g., with relevant communication skills to do so, a computer to access a survey) (iii) gender differences not being explored, (iv) potential non-transferability between educational systems and countries, (v) an overall small participants number which restricted granularity of data, and (vi) an exclusion criteria which limits the data range through subject specification criteria when final searched results are greater than 50. (2) Studies may not reflect the wider parental population due to the likelihood that parents taking part are action focused and hence may present a biased view. (3) Studies may not reflect the current diagnostic criteria and/or legal situation e.g., due to studies taking place before diagnostic criteria changes, changes in laws and/or changes in understanding and support. (4) Studies may not include individuals who are experiencing or have experienced traumatic incidents, as they may be disinclined to take part in a study. (5) A large proportion of studies (n=11) included participants who self-reported their autism diagnosis and research data, which was not verifiable. (6) Studies that involved focus groups (n=6) may have excluded some participants due to their social communication-interaction difficulties. (7) Studies relating to primary and/or secondary school experiences were limited to secondary (parental, staff) accounts of experiences (n=5), which may not have been a true reflection of the individuals true experiences. (8) All studies (n=36) were qualitative in nature which is not generalisable.

2.6 Recommendations for further research and practice

Some of the studies reviewed used semi-structured methodological approaches (n=14/36) that may limit storytelling and constrict experiences being shared. Focus group scenarios (n=6/36) may not have been suitable for some individuals who find group scenarios difficult. Thus, the main recommendation for future research and practice to come from this review is that a greater number of studies should consider using a narrative approach which allows for these unique first-person experiences to be explored whilst minimising the autistic barriers with communication. To represent the wider autistic population, it is essential that researchers provide a research platform that does not limit participation in any manner (table 2.5). An extensive list of specific areas that would benefit from future research is given in table 2.6. Researching these areas will provide a greater insight into the educational transitioning experiences of individuals, practitioners will then be able to understand and support their transitioning needs in a more efficient and efficacious manner.

Table 2.5: Summary of potential improvements that could be made to future research study methodologies that have been identified by this literature review.

Aim to ensure:

- Accessibility to the research methodology for individuals
    - Do not limit participation to online surveys so that individuals who lack a computer and/or computer skills can still be represented
    - In studies that involve focus groups, an alternative means of data collection are offered to those whose social difficulties may limit their abilities to express themselves in groups

- Autistic participants are recruited from a wide demographic range
    - Specifically, more studies involving primary-aged individuals to give first-person accounts of their educational experiences
    - Recruit from a wider variety of socio-economic backgrounds
    - Ensuring a balance of gender (equal male to female ratio)

- Autism diagnoses of participants in research studies are verified by an autism professional to ensure accuracy and consistency of data

Table 2.6: Alphabetical summary of the specific areas of research, which have been identified by this literature review, which require further exploration of individuals' (with autism) experiences in education.

- Barriers to disclosure of autism both inside and outside of their educational establishment
- Challenges linked to fine-motor skills
- Changing from full-time to part-time education at university
- Developing a positive self-perception of their autism and its contributing factors
- Discrimination
- Impact of academic curriculum changes
- Impact of and involvement in social activities linked to education both inside and outside of the academic setting
- Impact of having co-occurring conditions in combination with autism
- Impact of lacking foundations of English, math and/or science due to earlier primary educational challenges
- Impact of past experiences on future optimism
- Impact of receiving a late diagnosis within their educational journey
- Impact of the current diagnosis process, support and laws on the individual's experiences
- Internal-vertical day-to-day transitions
- Involvement of service providers and parents in transitions, both horizontal and vertical
- Literal interpretation of speech within the context of education
- Preferences for day-to-day communication in educational establishments
- Presentations of 'unacceptable behaviours'
- Reality of living away from home both on campus and off campus at university
- Self-advocacy in applying for, accessing, and using autism specific support
- Social support measures implemented
- Stereotypical, stigmatising and/or patronising behaviour towards them
- Teaching adaptions and styles
- The impact of positive changes in the life of an individual with autism
- Transition into FE and HE
- Types of academic support available, their usefulness and reasoning as to why support is not always accessed
- Use of sensory free spaces, activity groups, therapy groups and skills training

Conclusion

This literature review has highlighted that there are limited studies which document individuals' (with autism) experiences of change-transitions, with a predominant focus on their external-vertical experiences, rather than internal-horizontal or day-to-day, experiences. What is evident from the review is that individuals, in the main, experience academic and emotional-social challenges during their educational journey. The research papers in this review did not provide comprehensive insight into the unique experiences of singular individuals. Thus, this thesis aims to fill this gap in autism research, to explore what unique variables contribute towards individuals' educational experiences, and the impact that these might have on their state of health, both negatively and positively. In conjunction with the research, this thesis will also consider the influence of support practices, and the part played by the individual's 'self', particularly in relation to what being autistic means to them, getting diagnosed, disclosing, self-advocacy and what influences their resilience when faced with change-transitions. In addition, this thesis will provide participants with the opportunity to share their experiences prior to being diagnosed with autism, which the literature did not do.

Chapter 3: Methodology

3.1 Chapter overview

The methodology chapter will discuss the theoretical underpinnings in relation to investigating and analysing individuals' lived experiences. Theoretical concepts and models used to analyse experience, educational development, change and transitioning, will be explored. The decision to use a narrative analysis approach in the research design and philosophy will be justified, with researcher-participant relationship and researcher reflexivity being critically examined. Narrative interview designs, data collection, interpretation, holistic and categorical analysis, methods, will be investigated. Ethical and quality considerations will be accounted for.

The research methods (section 3.6) in this chapter will detail an exact overview of the research methods undertaken throughout, including purposeful sampling, participant criteria, recruitment, selection, setting and salient contextual factors. The narrative interview process, design, data collection methods, audio transcription, schema notes and reflective diary entries. Data interpretation and analysis, holistic-content, categorical-content, as well as the educational transitioning models, and critical narrative analysis methods implemented.

3.2 Introduction: Theoretical underpinnings of research

3.2 1 How to investigate individuals' lived experiences

Core to qualitative research is understanding the experiences of individuals,[231] something that quantitative research fails to capture.[232] Qualitative methods take an ideographic approach, in other words, they highlight unique elements. Thus, they enable researchers to focus on and investigate a participant's experience of *their* world from *their* perspective. An exploration of evidence-based literature reveals that a diverse range of qualitative approaches are available to researchers.

The anti-positivistic or interpretivist ethos, associated with qualitative research, posits that individuals' lived experiences, cannot be studied using traditional scientific methods and that, in order to build empathy with the individual, they must be studied within their natural settings.[233] However, the scientific principles that can be applied to lived experience research, are; (1) determinism, that the events under investigation have causes and (2) empiricism, that the origin of knowledge stems from experiences, insight into behaviour, which can then be classified, analysed, relationships can be discovered, a hypothesis formulated.[234] Research must be; (1) valid, in accordance with testing requirements, (2) grounded in empirical data, (3) parsimonious or, able to predict potential outcomes for participants, (4) verifiable, (5) functional, (6) encourage further research in this area.[235] An exception to general applicable scientific principles in this context is 'generality' which is not possible due to small participant numbers in the majority of qualitative studies. Pinnegar et al[231] and Smith[236] both emphasise that research which is not generalisable can still bring about profound change for individuals, by increasing understanding about their experiences.

Qualitative techniques used throughout research enable participants to share their perspectives about their lived experiences, often with the aim of promoting greater overall understanding of marginalised, disenfranchised, groups, a technique common in psychological research.[237-239] Erikson[240] and McAdams[241] emphasised the importance of a lived experience story as not only a means by which one can understand an individual's identity but also as a way in which an individual understands themself and are understood by others. Clandinin et al[242] highlighted the importance of lived experience research within the educational sector. They theorise that educational research has the potential to influence how other researchers will then view said experiences. Many lived experience researchers demonstrate the application of the principles of Deweyan theoretical beliefs, that they learnt by 'doing' their lived experience research, and how this then created opportunities for them to inform other lived experience researchers about the individuals being researched and their lives.[242-244]

3.2.2 How to analyse individuals' experiences, reality, 'truth'

3.2.2.1 Theoretical concepts of experience

> "*... experience is not something that belongs to or is had by individuals but rather denotes transactions in and across space and time within irreducible person-in-setting units; and it is perfused with affect that is not (only) the result of mental constructions…*" Roth et al[245(p106)]

There is no clear distinct theoretical framework for analysing experiences, however, theorist such as Dewey[246-248] have attempted to conceptualise individual 'experience', insisting that it cannot exist in isolation and that it will always involve human interactions of some kind. Dewey noted key distinctions, that researchers should be mindful of, when analysing experience data such as 'statements' made by participants, that one should not presume are the complete picture of their experiences, but simply 'signposts' towards multifarious 'experiences', that require further in depth investigation.[246] Hohr[249(p29)] proposed that the term 'experience' be replaced with 'feeling', made up of, "*action, emotion, cognition and communication…*" which "*…are intertwined and form an organic unity*". Hohr[249] reflected how this mirrored Dewey's proposal that cognition and emotion are inseparable parts which form an experience.

The principles of relativists, from the idealism and Deweyan perspective, are that individuals construct their subjective reality, meanings, and understandings, through their experiences within their social constructs, resulting in a 'protean reality', that is ever changing, due to every experience shaping its formation. Based on this theoretical assumption, it is vitally important that the researcher-participant relationship is reflected upon, as every interaction is likely to influence, and shape, participants' experiences and their conceptual reality.[250, 251] Analysing first-person accounts of lived experiences enables researchers to truly understand how participants formed their social reality and interpreted their world. A subjectivist philosophy of idealism, believes that every individual's experience, perception, of social experiences will differ greatly, resulting in the move away from generalisability of data to individual, specific, data, that encapsulates temporal experiences, over a time continuum, capturing the essence of a particular problem.[252] A naturalist epistemological approach, states that individuals are unable to separate themselves from their knowledge,[250] and therefore their reality needs to be investigated within its natural context, not in isolation.[250, 251]

An interpretivist (subjective) approach enables researchers to search for an individual's reality, their 'truth',[235] within the context of their lived experience. This approach hypothesizes that what an individual knows about their reality could not be separated from who they are, were, and what they deem their reality. That their 'truth', is intersubjectively acquired through social interaction and experiences, requiring the researcher to include and analyse in detail all interactions and experiences to ensure that participant data has true veracity.[232] Finally, according to inductive qualitative methods, lived experience data, should be gathered and interpreted through exact transcription of their spoken language as well as schema notes and reflective journal entries that comment on the expressions, phrases, verbal and non-verbal communication used, social information shared and the researcher-participant social interactions.[253, 254]

3.2.3 Theoretical concepts and models of use for analysing the lived experience, educational development, change and transitioning

3.2.3.1 Bronfenbrenner's bio-ecological model

In the 1970s and 1980s Bronfenbrenner suggested and developed what he named as his **ecological model**. The model provides researchers with a conceptual framework which they can use to gain an understanding about human development as a result of their lived experiences and interactions in their immediate and the wider environment.[255, 256] As outlined in figure 3.1 (a) the model illustrated that experiences are created within a collection of interrelating or nested systems namely the **micro-**, **macro-**, **meso-**, **exo-**, and **chrono-** systems that are organised in relation to distance from or potential to impact on the positive or negative development of a central individual (i.e., those layers closest to the individual having the greatest impact).

Firstly, the individual's **microsystem**, relates to their everyday settings (e.g., lessons in school, home setting) and those they have direct contact with (e.g., teacher, peers, parents, siblings etc). Data can be gathered about interpersonal interactions, meaningful behaviours, dyadic social interactions, and molar activities (perceived by the researcher as meaningful and intentional activities within the setting). This gives researchers insight into how participant experiences are shaped within their interpersonal structural context. Any role expectations expressed by participants in relation to themselves and others are also important details that should be included in the investigation, and how differing settings influence these. Secondly, data is gathered from an individual's **mesosystem**, this is how experiences interrelate between settings such as their school and their home, with a particular focus on the influence that each one has on the other. Thirdly, data can relate to their **exosystem** which are the external factors that influence their experiences. An example of this would be when investigating scenarios such as when participants are provided with additional external support such as educational funding to address specific needs or receiving medical interventions. Fourthly, the researcher investigates the individual's **macrosystem** which concerns the individuals perception of wider societies views about them (i.e., their disability if they have one), the impact that stereotypes might have on their experiences and whether this results in events such as bullying and/or discrimination. How the macrosystem influences the participant's concept of self is also included in this model. Finally, researchers consider the **chronosystem**, by investigating the 'complete lived experience', such as any environmental changes that participants experience throughout their life-time, any major events (e.g., changing schools, parents divorcing), and document how these may influence their life experience and their development.[255, 256]

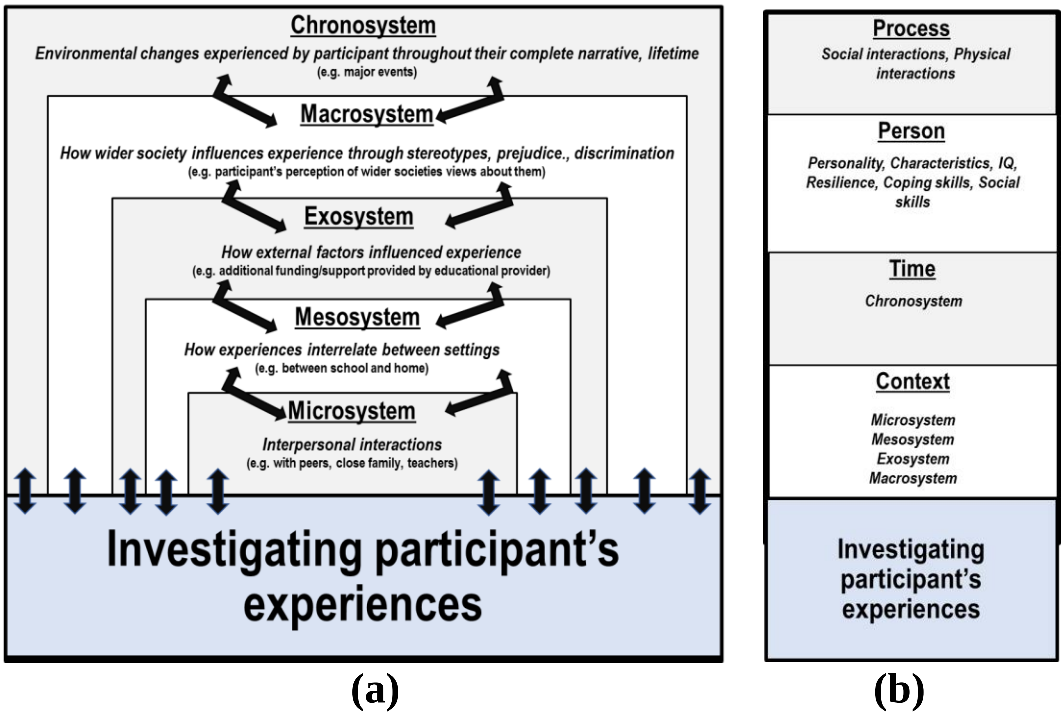


Figure 3.1 Bronfenbrenner's bio-ecological model (a) and process-person-context-time (PPCT) model (b). Adapted from:[255, 256]

In 1994 Bronfenbrenner further developed and renamed his model the **bio-ecological model**. As the name suggests, the revision shifted the sole focus of the environmental influences in an individual's development to also incorporate other realms of influence (e.g., personality, IQ, social skills).[255, 256] The addition became known as the **process-person-context-time (PPCT)** part of the model and its integration with the earlier version of the model is shown in figure 3.1 (b). Researchers could now investigate individuals' experiences within the **process** context relating to their social and/or physical interactions. It also allows any **person(al)** attributes revealed such as difficulties experienced due to factors such as having a disability, academic and emotional-social skills deficits, resilience, to be included. The change to the model ensures that a chronological framework is used to clearly identify 'time' elements within the social constructs of a participant's experience and that details relating to **contextual** information (micro, meso, exo and macro systems, as discussed previously) are also recorded.

3.2.3.2 Maslow's hierarchy of needs model

The **hierarchy of needs theoretical model** of Maslow[257] often guides researchers in the field of education, psychology and sociology, in analysing whether individuals are able to reach 'self-actualisation', their full potential, and if not what potential barriers prevent them from achieving this. This model, as outlined in figure 3.2, consists of areas that an individual must successfully achieve in order to reach self-actualisation, not a simple step by step process, as originally proposed by Maslow, but instead a holistic process whereby any setback in any area can prevent self-actualisation from occurring. (1) **physiological**, such as food, water, shelter, (2) **safety & security**, without fear of harm, (3) **love & belonging**, feeling that they belong and/or are loved, (4) **self-esteem**, having a positive self-esteem and concept of self, and (5) **self-actualisation**, being able to fulfil their complete potential.[257-259]

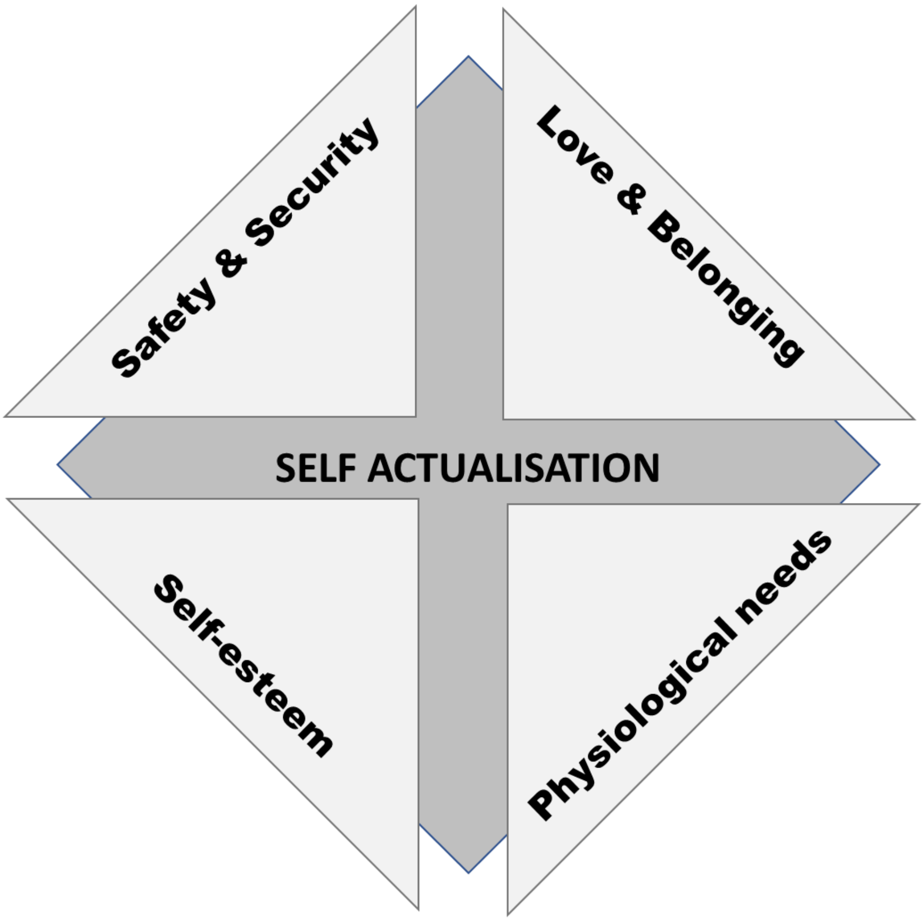


Figure 3.2: Maslow's hierarchy of needs model. Adapted from:[257-259]

3.2.3.3 J-curves and performance management

Davies[260] J-curve theory, and Kubler-ross[261] grief cycle theory, change curve, have formed the foundation of many modern change theories. To gain a complex understanding about the theoretical nature of individuals lived experiences relating to change, transitions, adaptive cycles, and the role that wider social contextual experiences play, researchers can encompass the works of Davies,[260] Kubler-ross,[261] Kilminster et al,[262] Ellaway et al,[263] MacGill,[264] and Prochaska et al.[265] In terms of experiences within educational settings, Kilminster et al[262] noted how transitions are 'critically intensive learning periods' whereby learners competence is not intrinsic, based purely on their abilities, but rather the result of the learning environment in which the transition occurs. Kilminster et al[262] continued by stating that the learner's ability to 'perform' is influenced by intrinsic individual changes, changes that come from within, as well as contextual changes, stemming from outside influencers. Ellaway et al[263] detailed how contextual change has a disruptive influence on a learner's ability to 'perform' in a new context, that there is a recovery period needed for every individual before they are able to return to their original state, and able to 'perform' to their full-potential. Figure 3.3 is an adaption of Ellaway et al,[263] 2017 model, visually demonstrating that when 'change' occurs this can have an impact on an individual's, academic and/or emotional-social 'performance' experience, which may drop to a lower level following the 'change'. As the 'performance' drops a period of 'recovery time' begins, during which time adaption and/or acceptance of the change takes place, before returning to originally state.

MacGill[264] theoretical perspective of change provides researchers with further insight into the impact of micro changes, how individuals can adapt during each cyclical stage dependant on key variables of potential, connectedness, and resilience. They theorised that individuals are only able to manage change, to reach their full-potential, when they possess key characteristics such as resilience or the ability to withstand the change, and connectedness or the ability to connect with those involved in the change. Another dimension that researchers may consider is the theory of Prochaska et al[265] who theorised that the movement of change occurs in a spiral of progressive stages namely precontemplation, contemplation, determination, action, and maintenance. The authors noted that many individuals don't simply follow a linear pattern and can relapse at any point during this spiral, resulting in them regressing to a previous stage.

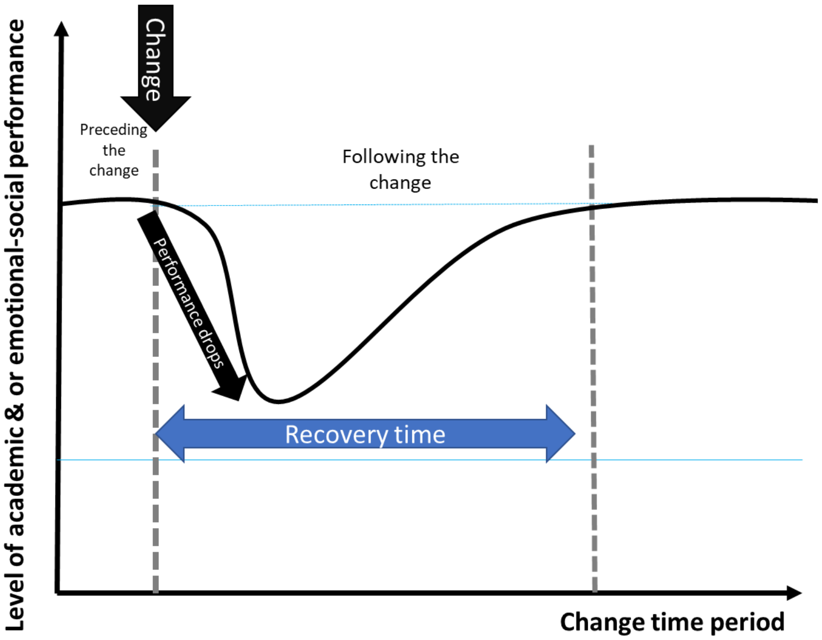


Figure 3.3: How change impacts performance during a transition. Adapted from:[263]

3.2.3.4 *Schlossberg's (Anderson) transitioning theory*

> "*Any event, or non-event that results in changed relationships, routines, assumptions, and roles*" Anderson et al[266(p38)]

Schlossberg's (Anderson) transitioning theory provides researchers with theoretical insight into individuals lived experiences through the **4Ss transitioning model**, which explores key variables influencing their transitioning experience, as illustrated in figure 3.4. Firstly, the **situation** is categorised as event or non-event that resulted in a change and categorises the variables associated with the change. Secondly, **support** refers to any social support available to the individual during the change. Thirdly, **self**, refers to the individual's personal characteristics and coping strategies in managing the change. Finally, **strategies** refers to an individual's coping responses as a reaction to the change.[266-268] To gain in depth understanding into an individual's ability to adapt to transition, researchers can use Schlossberg[268(p5)] 'model for analysing human adaption to transition' alongside a reworked model in Schlossberg[267(p61)] and

Anderson et al.[266(p38)] Schlossberg's theoretical model was originally intended for use in adults, however authors such as Winter[269] demonstrates how this can be adapted in the context of children.

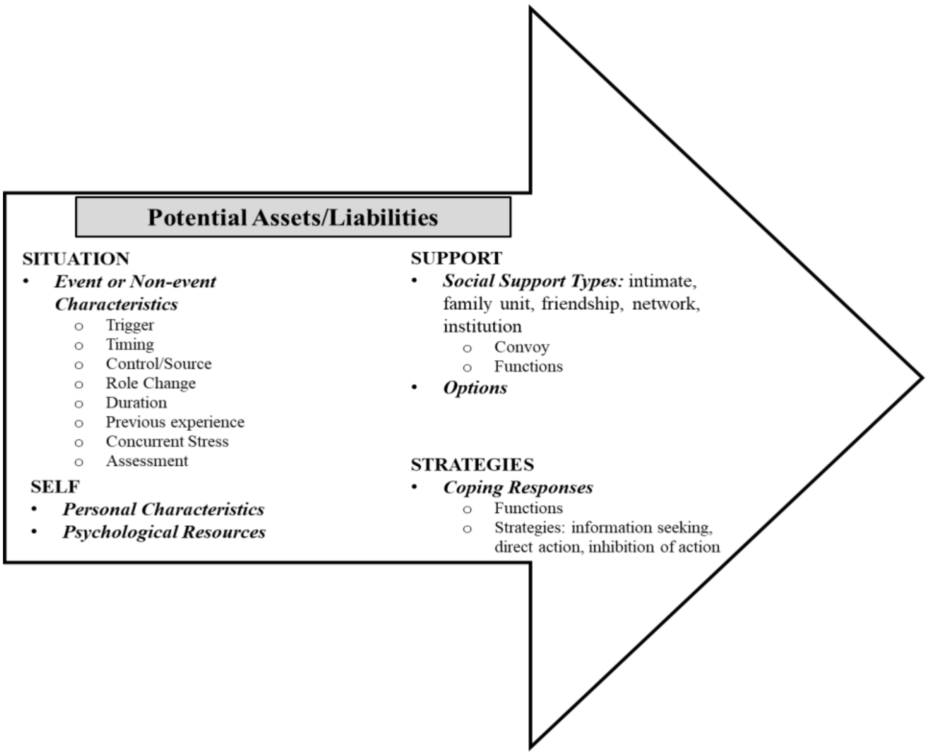


Figure 3.4: Individuals transitioning, adaption, potential assets, and liabilities. Adapted from: Anderson et al[266(p38)] (2011)

3.2.4 How to analyse individuals with a disability

To be able to analyse 'disabled' individuals lived experiences researchers consider the role that their disability plays, what terms like 'disability' infer, what being disabled means, critical theorist subjectivist viewpoints, social models of disability, and social role valorization. In society there appears to be a compulsion towards normalisation which influences individuals' reality and identity. Coch et al[270] raised the point, that the burden of responsibility to be 'normal' is placed on the 'disabled' child, and their parent, to fit into society, otherwise they are considered separate from the norm. Social theory of disability emphasises that 'disabled' individuals are oppressed, that their 'disability' is the result of the society in which they live.[271] Abberley[271] illustrated how terms like 'impairment', 'disorder' and 'disability' are social in origin, with society disadvantaging, disabling, individuals, who should be valued. The author pointed out that terms like these need to be politically addressed to change societal ideology and improve support provided, in turn positively improving ‘disabled’ individuals’ social experiences and their identity formation.

Critical interpretivist paradigmatic subjectivist viewpoint states that an individual’s social constructs are likely to have been shaped by how society views their ‘disability’, how they view them self, their reality, and the part that their ‘disability’ plays in their self-conception.[235] A subjectivist demonstrates how terms such as ‘ableism’ and ‘dis-ableism’, result in individuals being seen as ‘lacking’ in some way, resulting in discrimination due to their ‘impairments’.[272] Goodley[272] illustrated how society’s judgment of an individual’s behaviours as being ‘inappropriate’ and/or ‘challenging’ often resulted in ‘dis-ableism’ through exclusion. They believed that exclusion often occurred culturally, educationally, and socially, and that this has a predominant influence on the individual’s identity formation.

The social model of disability,[273] and social role valorization,[274] presents an advocacy participatory stance, which aims to empower participants through their first-person accounts. In general, there has been an international shift in attention on the impact of disabilities and how impairments can influence social inclusion and result in health disparities. This has led to increased demand for research in this area that includes the ‘disabled’ individual, in order to gain first-person insight into, and greater understanding about, the influence that their ‘disability’ has on their life.[239, 275] Thus, ‘disabled’ participants lived experiences to provide evidence based findings that have the potential to positively inform, and influence, future policies and practice.[276]

3.2.4.1 The said and un-said

Researchers investigating individuals lived experience ensure that they gather and interpret data on both their ‘said’ and ‘unsaid’ communications, including data on their body language or actions, such as withdrawing, clapping, rocking, and are mindful that these are equally as important as the words that they use.[16] Thus, qualitative methodologies and analysis need to ensure these factors are accounted for so that participants’ voices can be truly heard.

3.2.4.2 Proxy parental perspectives

Exploring and understanding what shapes a participant's identity, their ability to accurately recall events from their lived experience, is core to a qualitative analysis researcher and its research aims. McLean et al[277] identified three factors influencing a life narrative that researchers should consider namely (1) motivational, and affective themes, which are influenced by an individual's well-being, (2) autobiographical reasoning and structural aspects and (3) personality traits. The autobiographical reasoning, or memories, from early childhood are believed to be shaped by joint reminiscing between key family members and the child, with the key family member modelling how a story is told, what to include, exclude and accentuate.[278]

Episodic memory difficulties and individuals with autism

Literature indicates that individuals with autism have significant social communication and interaction difficulties which are likely to make joint reminiscing with their key family members difficult, especially during their early childhood[87, 88] and that this has the potential to lead to difficulties in forming their early autobiographical memories. Research also indicates that episodic memory impairments can exist for these individuals[279] as a result of their neurological functioning, which is known to have a significant effect on their ability to recall emotional and/or social encounters.[280] Such findings support the use of a research methodology that includes proxy data, such as parental interview data, to help fill-in any episodic memory gaps.[281, 282] However, it should be noted that, there is substantial evidence demonstrating how proxy perspectives often differ considerably from a 'disabled' individual's perspective about their lived experience which leads one to question the accuracy, reliability and trustworthiness of solely using proxy parental research studies in representing the true lived experiences that first-person accounts are crucial in providing.

3.2.4.3 Individuals with autism and cross-cultural boundaries

> "*If we begin to understand the framework that lends meaning to these lives, then we have taken the important first step to being able to access the wider framework of meaning that is the binding agent of a culture*"
> Andrews[283(p491)]

Qualitative researchers often find it difficult to comprehend what factors have the potential to influence an individual's formation of meaning and knowing, due to cross-cultural boundaries between the researcher and their participant which has the potential to limit their ability to accurately interpret and analyse data.[283] It is essential that qualitative researchers attempt to imagine what the participant's world, is like, to gain greater insight. Some literature postulates that there is a 'culture of autism',[284] that individuals (with autism) may be part of a separate cultural group, within which they have shared ideas, customs (rituals and obsessions) and social behaviours. However, there are limited research studies in this area making it difficult to establish whether theoretically a 'culture of autism' does in fact exist.

3.3 Research design

3.3.1 Research philosophy

My (the researcher's) theoretical perspectives, as demonstrated in figure 3.5, is ontologically subjective,[232] relativistic,[250, 251] epistemological interpretivist,[235] naturalist,[250, 251] ideographic,[243] and anti-positivistic.[233] As this research is specifically about individuals with autism who have a 'disability', a critical interpretivist and advocacy stance has been adopted. Theory of disability,[271] the social model of disability,[273] social role valorization (SRV),[274] subjectivist viewpoints of 'ableism and dis-ableism'.[272] These all contributed towards the ethos of this research, which aims to contribute to research in this area, to influence policy makers, to improve understanding about individuals with autism (from their first-person perspectives) and to encourage the implementation of strategies that will reduce existing disabling barriers.[275] The research philosophy has guided my understanding about how individuals with autism shape their identity and has highlighted the importance of analysing societal factors and experiences, in depth, to discover what shapes an individual's reality and identity formation.

3.3.1.1 Addressing 'dis-ableism', changing societal ideology, promoting understanding about differences and difficulties

> "*To understand the lived experiences of people with disabilities, more qualitative research is required. Measures of the lived experience of disability need to be coupled with measurements of the well-being and quality of life of people with disabilities. To better understand the interrelationships and develop a true epidemiology of disability – studies are needed that bring health condition (including co-morbidity) aspects of disability into a single data set describing disability, and that explore the interactions between health conditions and disability and environmental factors… Well designed, qualitative research can be used to investigate the full range of barriers and document good practices*". World Health Organization[275(pp46-47)]

Recommendations made by the World Report on Disabilities[275] have been included in the research design, ensuring that participants were able to share their life narrative, as well as considering, any co-occurring conditions, their mental health, well-being, quality of life, family, educational environment and any potential barriers in their educational journey. The design aimed throughout to address 'dis-ableism', to change societal ideology, to promote understanding about differences and difficulties (D&D) that individuals with autism may have and, in turn, improve support provided. By sharing participants lived experiences, in the context of this research, participants have been provided with a platform to break down the societal barriers experienced by them due to their 'disability or disabilities', to fight discrimination and improve the lives of other disenfranchised individuals. As a researcher, I refuse to substantiate socio-therapeutic theories that devalue 'disabled' individuals by viewing them as having 'problems' because of their 'disability' and wish to avoid the perpetuation of such inequalities.[285]

Central interest of this research has been to investigate the lived experience of individuals with autism transitioning throughout education. I have been mindful that participants have a complex neuro-developmental 'disability', with significantly impaired social abilities, often presenting with receptive and expressive communication D&D. I ensured that participants were given an effective research platform in which they could fully express 'their voice' and that, as the interpreter of this data, I was able to reflect its authenticity.[286]

Based on episodic memory difficulties this research used proxy parental accounts of lived experiences (life narratives), not in isolation but rather to supplement and/or expand on participants' first-person accounts. The inclusion of proxy parental perspectives was to supplement participants life narratives where applicable, not to replace participants' data, and was not used as a stand-alone source of qualitative data.[287] Concern for individuals with autism was a key attribute of this research which was why an interpretive paradigm was vitally important. Thus, this research did not simply accept the educational transitioning processes that existed for participants but questioned these in the context of critical theory and disability studies. The research aimed to gain a wider theoretical perspective on the inequalities encountered by individuals with autism, not only within the educational sector but also society in general, with the goal of producing findings that could act as a catalyst for positive transformation in such sectors.

3.3.2 Prior to the narrative analysis approach

Before embarking on a qualitative study, I needed to evaluate which qualitative approach was most effective in meeting my research aims and document theoretical evidence to justify my decision. Following on from the preliminary study (see appendix 3.1), as well as a growth in my understanding (appendix 3.2), I investigated the most appropriate qualitative research method to use (table 3.1), and it became clear that a narrative analysis (NA), or life narrative approach was the most appropriate. This approach was deemed the most efficacious approach because it enabled data from participants to be gathered on an individual case basis and analysed in a manner most likely to reflect a true representation of their unique lived experiences.[244]

Table 3.1: Evaluation of qualitative approaches best suited to meet the research aim.

Qualitative approach	***Description of approach***	***Evaluation in context of research aim***	
		Does it meet the aim?	***Further clarification***
Case Study	*Produces data about individual participants' experiences*	Yes	
Ethnography	*Focuses on cultural-sharing within a specific group*	No	
Grounded theory	*Produces a theory about lived experiences of participant group*	No	Aim of this research is to investigate individuals' unique experiences not to produce a theory about lived experiences
Phenomenology	*Focuses on the essence of a group of participants' experiences, something they have in common, a specific phenomenon*	No	Aim of this research is to investigate individuals' unique experiences not to investigate a phenomena
Narrative	*Produces detailed data about each individual participants' unique lived experiences*	Yes	

Adapted from:[232]

3.3.3 The narrative analysis approach

The narrative analysis (NA) approach enabled me to investigate individuals' lived experiences, first-person accounts, and provided data that gave insight into their subjective experiences. NA is illustrated in literature as an appropriate research method when aiming to understand human experiences, with some theorists agreeing that individual narratives are a valuable source of empiric data[231, 252, 288] and that they have "*…'realist', 'modernist', 'post-modern', and 'constructionist' strands…*" even though some "*… scholars disagree on origin and precise definition*" Clandinin et al.[242(p37)] Although, something that many theorists disagree on is the detailed definition of NA research, which varies according to their research discipline, their paradigmatic view point (worldview), their investigatory stance,[289] their ontological positioning with regard to the nature of reality and epistemological constructive perspective about the relationship between the researcher and the participant.[290] As a positive by-product of the growth in my knowledge, resulting from this research, there was the intentional benefit of improvement in the professional effectiveness and efficacy of my role as an autism university practitioner. Polkinghorne[291] supports this dual role as a researcher and an autism practitioner, highlighting how participants' narratives provide practitioners with greater insight into individuals' behaviour. In conjunction with this, this research aimed to benefit the wider university's autism related policies and practice, as well as in my self-employed role as a private neuro-diverse consultant and trainer. I aim to endeavour to share good practice with others, individuals, parents, organisations, schools, further education (FE) and higher education (HE) establishments.

3.3.3.1 Researcher-participant relationship

Historically social scientists' understanding about researcher-participant relationship has changed overtime. In the nineteenth century they attempted to use physical science methodologies within their field which adhered to an objective realist stance. They postulated that the relationship that exists is; (1) bounded (what the researcher and participant know are not connected), (2) static (lacking in movement or changeability), (3) atemporal (not related to time), (4) decontextualized (occur in isolation), and that (5) findings could be generalised in certain conditions.[236] However, as a narrative researcher I opposed this belief and their idealist relational perspective, I perceived the relationship between the researcher-participant as being; (1) unbounded, whereby we were not distinct separate entities, (2) changeable, (3) temporal, (4) contextual, (5) not generalisable, as distance between the two of us could not be guaranteed with every interaction potentially influencing the findings.[236]

The 'narrative turn' presented historically in literature, illustrated to me the changing relationship between researcher-participant,[231, 292] a change in the understanding of lived experiences through spoken language (words) rather than numbers[291, 293-295] and a change in conceptualisation about the researcher-participant relationship.[231] As a narrative researcher I was mindful of this 'narrative turn' in how I interpreted the meaning a participant assigned to their experience.[296] I recognised that as a researcher I needed to, work in collaboration with a participant and that this results in a shared power dynamic.[296] I postulated that the relationship between myself and a participant was not static or atemporal, it was changeable, that every human interaction always influenced each other at varying points in time within our lives (in the context of the research interaction).[231] My subjective stance, also highlighted that I was unable to maintain an objective positivistic stance during this narrative research because the researcher-participant relationship was inseparable.[250, 297]

Cautions of narratives

Some academics argue that due to the NA researcher-participant not being able to distance themselves from each other, that this results in unreliable and biased data.[231] To counterbalance these views, it was important that I documented specific strategies used throughout the research to clearly outline and demonstrate the research's quality. I demonstrated throughout that the research has credibility, confirmability, dependability, transferability, and plausibility. Which was achieved by implementing strategies such as selection criteria that was based on purposeful sampling and literature relevant to this research, using narrative interview questions that were designed to elicit 'story telling' about experiences with open-ended data analysis and participants checking their interview one transcript for accuracy through a means called 'member checking'.[290] This took place during interview two (as detailed in appendix 3.5 (a)) to ensure that the findings could be justified as being a reflection of their authentic experience.[231]

Some academics argue that NA researchers having an insider perspective which impacts their values, assumptions, beliefs and potentially leads to biases, which in turn may negatively influence the participant’s ability to accurately recollect and describe their experiences.[298] I posed a common counterargument to this, found in literature, that by having this insider perspective I also had the skills necessary to quickly develop rapport during an interview.[299] I believed that such empathetic connections between myself and the participant was key to unlocking truthful accounts of experiences, improving research outcomes[298] and that without this connection participants were likely to withhold valuable data due to negative feelings associated with the information.[300] I was mindful that any professional relationship that I had with any participant could potentially impact their responses, our researcher-participant relationship, as well as how I interpreted their data.[301, 302]

3.3.3.2 Researcher reflexivity (as illustrated in appendix 3.3)

The researcher as the data collection instrument

Key to NA is data collected by the instrument for collecting this, the researcher. I, as the researcher, was responsible for deciding what areas needed to be explored. Academics agree on the importance of the researcher as an instrument within the interview study to encourage conversation, openness, rapport and trust however what they disagree on is what this relationship should look like.[303] Many believe that my role should be one of collaborator rather than solely being an interpreter, analyser, of participant data, where I aim to have an equitable relationship with the participant or an equal balance of power. With the researcher using the research to give the participant a platform to be heard and faithfully represent their experiences in the reported findings.[304] Some academics argue that it is impossible for the researcher to solely be a collaborator and elements of interpretation are essential which was why I involved the participant in as many stages of data collection as possible, through member checking and through exact participant quotes throughout.[290]

Researcher reflecting on their: values, assumptions, beliefs, and biases

The literature states that to evidence reliability of NA research I must reflect upon my values, assumptions, beliefs, and biases throughout my research,[305, 306] and how the aforementioned researcher-participant relationship may affect participants' stories told. This potential influence was considered at every stage of the research namely participant recruitment, participant interviews, methods implemented, data analysis, interpretation of data and the reporting of findings.[307] This was done through schema notes and reflective diary entries, and demonstrated transparency about factors that may influence the research.[253, 254] My supervisory sessions were often utilised as a means to debrief and to monitor the aforementioned factors as my PhD progressed.[308]

Researcher's research design

> "*To idealists, instruments do not have a standing independent of what they are designed to measure*" Smith[236(p9)]

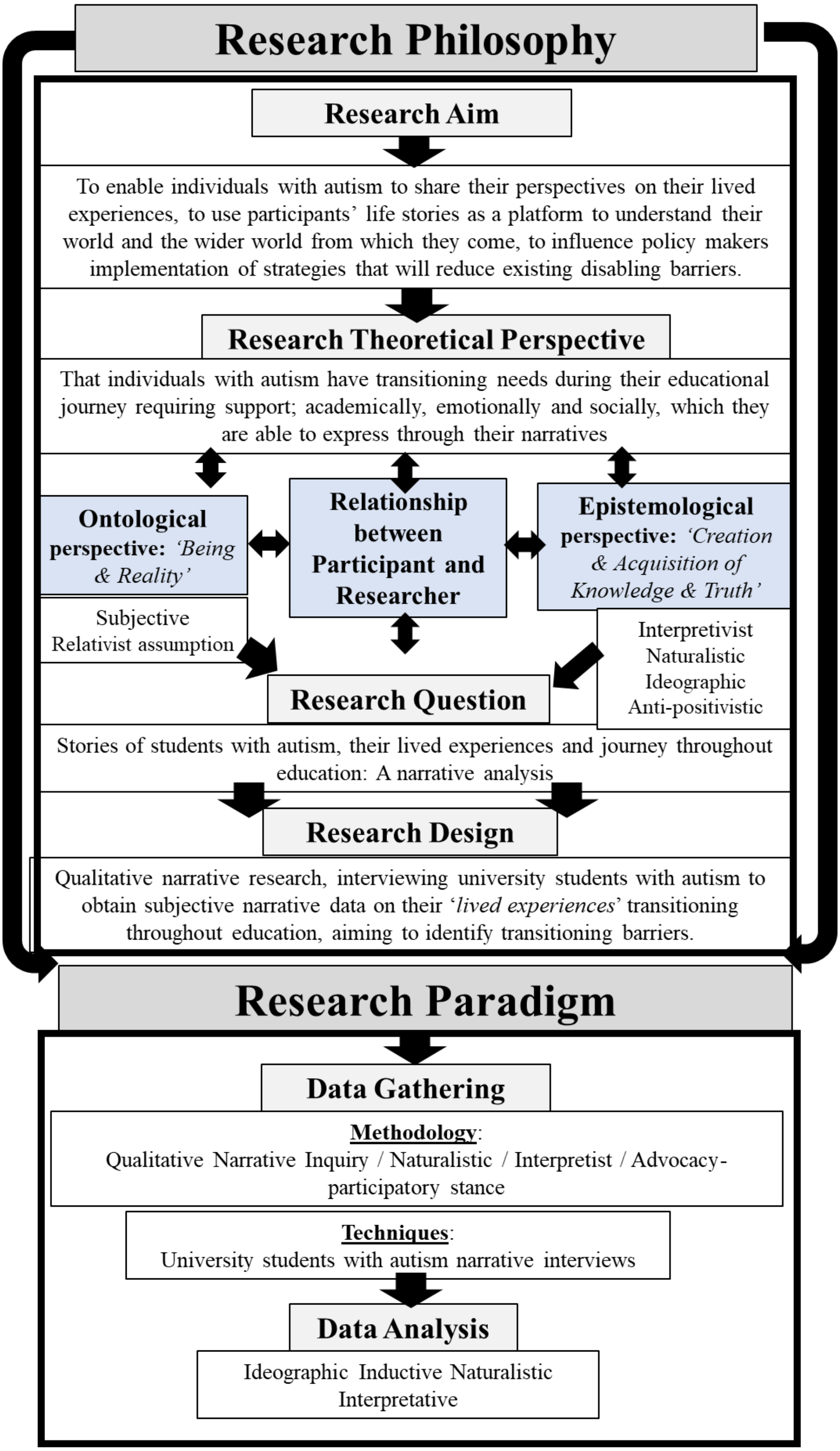
As a researcher I have been reflexive within the research design, and my researcher-participant relationship, adhering to the 'Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist', as detailed in appendix 3.8. Due to my personal and professional experiences, this research has placed considerable importance on supporting individuals with autism transitioning throughout education. These experiences highlighted that something needed to change in the current British educational system. One might argue that I have a biased view of this educational transitioning journey and that this may not truly represent the experiences of all individuals in the UK. The participant, and their parental figure, might also have viewed me as 'one of them', as an insider, with similar experiences and a deeper understanding about autism. Both of these points highlighted to me the importance of transparent researcher reflexivity throughout this research to ensure that participants' experiences in this research were truly reflective of the majority, as noted in appendix 3.4.

My vast experiences working with individuals with autism, my in-depth understanding of autistic communication needs, meant that I could use appropriate communication techniques that not only encouraged 'story telling' but also enabled it. For example, I was able to use non-abstract language which was clear and concise, and redirection communication techniques when participants were stuck on an obsessive point.

Sharing of life experiences had the potential to open-up emotional memories for participants that may need further support, which was accounted for in the research design and ethical application. When deeply distressing, emotional and personal information was shared by a participant then I listened and was non-judgemental. When my opinion was requested by a participant, I used deflection (reflection) to avoid influencing the narrative being told, e.g., Q: Don’t you think that was really bad? A: It sounds to me like you felt it was really bad. The nature of communication and interaction used between myself and participant sometimes elicited me sharing something that I had experienced to build rapport and encouraged a sense of alliance. My background professionally and personally enabled me to have an in-depth understanding of the participant’s world, which helped me to establish rapport and trust in an effortless and expeditious manner. At the end of all interviews, I ensured that the participant had been given plenty of time to ask any questions, and I proactively emphasised and reflected back any positive achievements shared by the participant to encourage a congenial ending to the interview relationship.

Researcher reporting data

During the report writing phase I needed to relate participant experiences to literature and theory. Review criteria such as JBI (Joanna Briggs Institute),[185] CASP (Critical Appraisal Skills Programme: Qualitative Checklist),[309] SRQR (Standards for Reporting Qualitative Research),[310] was used to ensure standards of reporting of qualitative narrative data were met.[250, 251] It was essential that I thoroughly accounted for my role, demonstrated honesty and gave a faithful representation of participants’ experiences which was why, when any elements of potential researcher bias were identified, this was acknowledged and critically reviewed in light of other research.[304]



To enable individuals with autism to share their perspectives on their lived experiences, to use participants' life stories as a platform to understand their world and the wider world from which they come, to influence policy makers implementation of strategies that will reduce existing disabling barriers.

That individuals with autism have transitioning needs during their educational journey requiring support; academically, emotionally and socially, which they are able to express through their narratives

Stories of students with autism, their lived experiences and journey throughout education: A narrative analysis

Qualitative narrative research, interviewing university students with autism to obtain subjective narrative data on their '*lived experiences*' transitioning throughout education, aiming to identify transitioning barriers.

Figure 3.5: Research Philosophy and Paradigm.

3.3.3.3 Setting/site and salient contextual factors

Due to the interpretative nature of qualitative research it was essential that the research design took a naturalistic approach,[254, 308] that I studied the participants in their natural setting, wherever possible to do so. This approach helped participants to feel relaxed, to free them from distractors[311] and, hence, provided me with an opportunity to observe cause-and-effect through participants' spoken communication, intonation, and non-verbal communication.[251] I consciously created an interview environment that encouraged an empathetic connection with the participant. Thus, overall, this approach aimed to maximise my insight into participants' experiences and improve the overall productivity of the interview.[312]

3.3.3.4 Narrative interview design

This narrative analysis (NA) research was designed in line with the recommendations made by Pinnegar et al,[231] adhering to a narrative interview design by interviewing participants using questions and prompts. It gathered participant subjective narrative data on their lived experiences, whilst ensuring that the narrative interviews enabled them to fully account for their experiences and, ultimately, identify transitioning barriers experienced by them during their educational journey. A naturalistic narrative interview inquiry method was considered the most appropriate NA approach best suited to gather data addressing the research question. It provided a "*comprehensive and contextual understanding of a phenomenon. No individual positivist paradigm could provide the level of detail achieved in a naturalistic inquiry*" McInnes.[251(p36)]

Methods implemented enabled participants to share their first-person perspective, with member checking (as discussed in section 3.3.3.1 sub-section 'cautions of narratives' and in appendix 3.5 (a)), and proxy 'parental figure' perspectives were used to support any episodic memory gaps (see section 3.3.3.8). Psychosocial influential variables linked to autism that had the potential to influence participants thoughts and behaviours, were considered and included in this research when relevant to do so.[240] These variables included neuro-developmental delays, neurological differences that impact grey matter development and maturity, educational demands that didn't account for neuro-psycho-social age, their families perspective of autism, the media's perspective of autism, co-occurring psychological and psychiatric conditions, as well as all other relevant social influencers. In addition to this, I considered participant's 'transitions through points of crisis', that may have occurred during stages in their 'life cycle', in accordance with Erikson[240] theory.

I took a reflexive perspective during the course of the interview(s), noting that a chain of cause-and-effect necessitated self-reflection and self-analysis throughout, as a means to acknowledge my influence on the participant and vice versa.[254] This narrative research design ensured that maximum flexibility was possible during the interview(s) so that participants were able to share their experiences freely without feeling constrained by a rigid interview framework, with occasional prompting from myself when needed, to ensure that they stay within the research aims and objectives.

3.3.3.5 Narrative data collection

This research aimed to faithfully record the voice of the research participants, transforming their literal spoken word meticulously, through an independent transcription service, into a credible written academic format. Müller et al[313] highlighted the importance of investigating my dual role as a reflexive transcriber and the theoretical considerations of using transcripts, as a method of data collection. This involved considering (1) the transcript, purpose, final product, processes involved, role of transcriber, (2) the relationship, between reader of transcription and participant's voice, which will be discussed in detail in the following sections, and (3) other practical considerations. In terms of practical considerations in the context of this research transcription I considered all ethical procedures prior to interview, including the interview design, prompt questions used. These clearly outlined what I aimed to record which was then transcribed and why. Through the Swansea University Assessment Centre, I was able to source a registered and licensed transcription service and, through this service, ensured accurate and credible transcriptions were produced that met quality criteria of the research study. To further reinforce reliability and quality of transcribed data, I also checked all transcriptions with their audio recording, as detailed in the narrative interview section 3.3.3.4. Data collection methods are detailed in appendix 3.5

(a). Storage and management of recorded audio files, and transcribed data from each editorial stage, was essential (as outlined in section 3.4 and appendix 3.7).

Throughout data collection I was mindful of a number of points. Firstly, that some of the participants' experiences may have been inexpressible, meaning that they may have not been able to put them into words, that they were ever changing, influenced by interactions, thoughts, environmental transactions (personal, social, and material), temporal in nature, and evolved through time. Based on this I ensured that I wrote detailed schema notes and reflective diary entries. Secondly, that some experiences were constantly transforming because of every experience encountered, including the researcher-participant interaction. Based on this I ensured that I reflected on my researcher-participant relationship throughout. Thirdly, that data collected during an interview occurred on an ontological continuum "*… a stream of experience that generates new relations that then become a part of future experience…*", necessitating that I accounted for and were mindful of the fact that the narrative "*... inquiries are themselves a form of relation that can and should be questioned in the course of ongoing research*" Clandinin et al.[242(p41)] As well as following the principles of Deweyan theorists in the context of their 'Continuity and Interaction', I ensured that essential narrative data was included within the participant's narrative, through schema notes and reflective diary entries, such as any "*…tension at the boundaries*", any continuity tension made up from "*temporarily, people, action, and certainty*", and any interaction tension made up from, "*context, people, action and certainty*" Clandinin et al.[244(p21)]

3.3.3.6 Narrative data interpretation and analysis design

To gain knowledge and understanding about the identity and reality of every participant's lived experience, an ideographic inductive research design strategy was used, as recommended by Hiles et al.[314] This research strategy was designed to systematically gather data that was then analysed and resulted in a complex understanding of the subjective meaning given by each participant about their transitioning experiences,[315(p371)] as cited in.[316]

Prior to analysis, research participants' narrative interview transcript data was combined with my schema notes and reflective diary entries to provide me with additional detailed data on contextual elements and nuances of meaning, as well as being supplemented by parental figure(s) interview data. I analysed this data as a means to interpret how a participant made sense of their experiences, delineated through exact transcription of spoken language, as well as through notes made on expressions, phrases, verbal and non-verbal communication used, social information shared, and researcher-participant social interactions.[253, 254]

The NA methodological approach, and theoretical considerations made, in terms of participant 'identity and reality', specifically aimed to ensure that the data collected accurately represented individuals true reality, and that this data enabled me to accurately compare participant cases to consider if overarching themes were present, in the context of evidence-based literature. As detailed in appendix 3.5 (b). This NA data was later considered in the context of other participants' data to identify if transferability between participants and situations was possible,[250] as opposed to generalisable data that could be applied to other settings,[250, 251] with the ultimate aim of bringing about profound change for individuals.[231]

Holistic and categorical consideration

Based on the work of Lieblich et al,[317] Beal,[318] Hiles et al,[314] Labov[319] and Polkinghorne,[320] participant case data was analysed using holistic and categorical analysis.

Firstly, a holistic approach was used to analyse the participant's whole narrative through their transcribed 'text' (spoken) and non-verbals (as noted in reflective diary entries and schema notes), aiming to discover narrative changes through time, and how these joined to form their complete narrative. Holistic-content analysis (HCA) approach analysed the core themes that when joined together formed the whole educational journey. Throughout the thesis, these are termed 'core transitioning themes' (CTT). Holistic-form analysis (HFA) approach analysed significant experiences that took place throughout the whole narrative, demonstrating times where there was narrative cohesion, turning points, progression, or regression, as well as changes in participant's identity and perceptions.

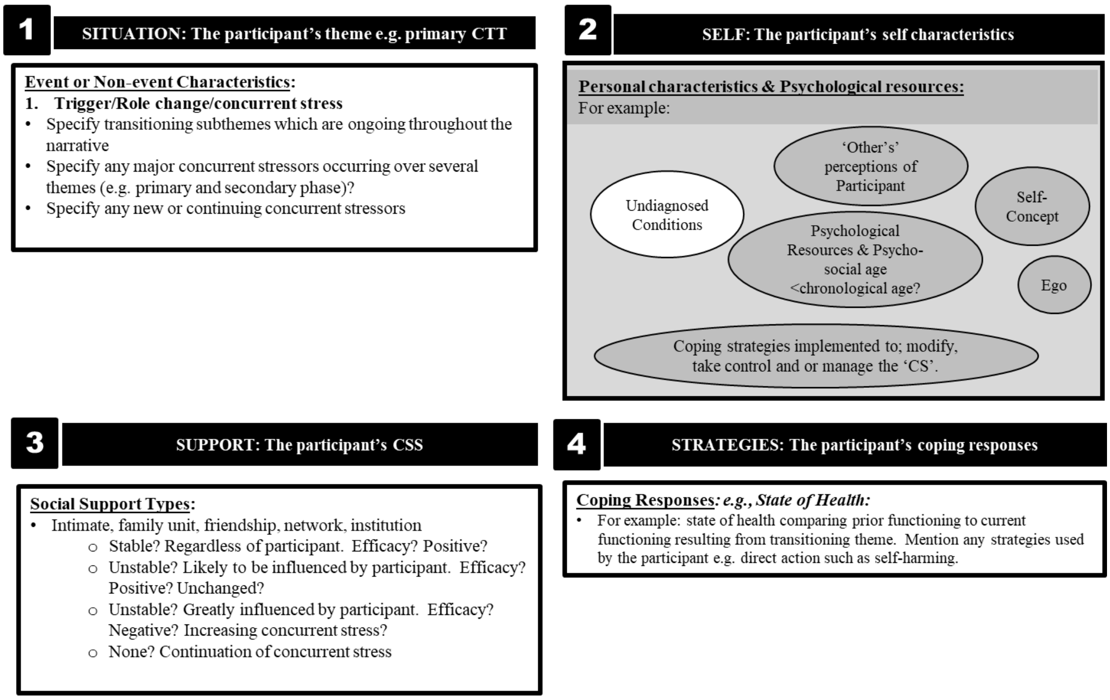
Secondly, a categorical approach was used to analyse the events that occurred within the participant's narrative, which were grouped into units of similarity. Categorical-content analysis (CCA) approach analysed the essence of participant's experiences, by breaking their transcribed text (spoken) and non-verbals (as noted in reflective diary entries and schema notes), into what is termed throughout the thesis as 'transitioning sub-themes' (TST), which contained narrative identified potential causes of stress otherwise known as 'concurrent stressors' (CS). Categorical-form analysis (CFA) approach analysed the linguistics or non-verbals to look for evidence of the emotional significances of participant's experiences, that written transcription data on its own may not have revealed.

3.3.3.7 Application of the theoretical models for analysing educational development, change and transitioning in the research design

Characterising the transition

This research did not simply recount participants educational transitioning experiences verbatim, it used relevant theoretical transitioning models and models of cyclical change, to account for and analyse, any complex data variables that occurred in experiences shared. Descriptions of the various models applied are detailed earlier in this chapter. In conjunction with the ethos of Schlossberg's theory,[266-268] I did not simply focus on external-vertical transitioning, from one educational phase to another, but also analysed internal-horizontal transitions, linear transitions, day to day transitioning experiences of participants.

Schlossberg's transitioning theory,[266-268] with its core identifiable transitioning categories of situation, support, self and strategies (figure 3.4),[266] was adapted into an 'educational transitioning model' for analysing participants' data, as illustrated in figure 3.6. The method for use within this study is discussed in more depth in appendix 3.5 (c). Within the context of this transitioning model particular attention has been paid to incorporating or accounting for concurrent stress (CS) triggers, self-characteristics ('**undiagnosed**' CS), concurrent stress support (CSS) provided, and coping strategies implemented by the participant. Bronfenbrenner Bio-ecological and PPCT model,[255, 256] also contributed to the formation of this adapted or usable ‘educational transitioning model’ with particularly attention given to participant data that reflected the part played by the micro-, meso-, exo-, macro-, and chrono- systems, and the process, person features.


1 SITUATION: The participant’s theme e.g. primary CTT

Event or Non-event Characteristics:
1. **Trigger/Role change/concurrent stress**
- Specify transitioning subthemes which are ongoing throughout the narrative
- Specify any major concurrent stressors occurring over several themes (e.g. primary and secondary phase)?
- Specify any new or continuing concurrent stressors

2 SELF: The participant’s self characteristics

Personal characteristics & Psychological resources:
For example:

3 SUPPORT: The participant’s CSS

Social Support Types:
- Intimate, family unit, friendship, network, institution
    - Stable? Regardless of participant. Efficacy? Positive?
    - Unstable? Likely to be influenced by participant. Efficacy? Positive? Unchanged?
    - Unstable? Greatly influenced by participant. Efficacy? Negative? Increasing concurrent stress?
    - None? Continuation of concurrent stress

4 STRATEGIES: The participant’s coping responses

Coping Responses***: e.g., State of Health:***
- For example: state of health comparing prior functioning to current functioning resulting from transitioning theme. Mention any strategies used by the participant e.g. direct action such as self-harming.

Figure 3.6: Educational transitioning model. Adapted from:[255, 256, 266-268]

Adapting to the transition

This research design did not simply recount participants adaption to transition verbatim, it applied Maslow’s[257-259] hierarchy of needs model, as an analytical tool to identify what variables prevented participants from reaching their full potential, and to potentially address these barriers to identify whether support was needed. Application of Ellaway et al,[263] model (figure 3.3) was also included where relevant, as an analytical tool exploring the impact that change had on a participant within the context of their narrative, in terms of their, academic and/or emotional-social experience (performance), how long it took them to adapt following a change, and to identify any support needs. To gain further insight into participant’s relationship to change the research analysis was mindful of MacGill[264] theoretical perspective which considered the influence of key variables of potential, connectedness and resilience and Prochaska[265] theory which considered the movement of change as a spiral of progressive stages of precontemplation, contemplation, determination, action, maintenance.

3.3.3.8 Interpreting and analysing conversational text

Literature on how to analyse conversational text for narratives was included in this design. This included elements of ‘story boundaries’ or beginnings and ends,[321, 322] the chronology of events[319] and ‘storying stories’ or looking at narratives through multiple lenses.[323] Interpretation of participants narratives followed the principles of ‘re-storying’[232] and was guided by the following frameworks:

- Ollerenshaw et al[324] e.g., determinants; characters, setting, problem, action, resolution
- Clandinin et al[252] e.g., three-dimensional approach of interaction (personal/social), continuity (past, present, future) and situation

The various differing methodological approaches considered during the NA of transcripts were discourse analysis methods,[319, 325] text analysis based on structural elements,[326] three dimensional space,[244] and life course stages, experiences.[327] Throughout the NA participants key experiences, resulting from events occurring in a time frame, were categorised as narrative features by myself, the researcher, before meaning was interpreted. I investigated every narrative feature in the context of its past, present, and implied future. My NA approach differed from post-positivist, as it paid detailed attention to context, something that post-positivists in general limit.[242, 244]

This research interpreted the participant’s voice, through discourse analysis, as a means to identify patterns.[328] I identified narrative threads, analysed them, not only from participant’s transcribed words but also through my schema notes and reflective diary entries, which were vital for documenting participant’s use of language in telling their story, the ‘said’ and the ‘unsaid’. I investigated narrative features within the participant’s story, through its fabula content, “*breaking text into smaller units of content and submitting them to … descriptive treatment*” Lieblich et al.[329(p112)] Throughout the interviews, and NA stages, I looked out for signs of unconscious soliciting by paying particular attention to two major narrative threads, identified by Rogers,[328(p111)] firstly, “*knowing, not saying, and writing*”, secondly, “*not knowing,* *not saying, and denial or erasure*”, and I utilised parental figure interview data to fill in any episodic memory gaps.

To ensure participant’s data reflected their lived experience, I collaborated with them, interpreting their story through exact quotes and observational notes on non-verbals, I paid particular attention to their thoughts, feelings, emotions, actions, and interactions as well as the social structures in which their stories were located, including their achievements and challenges. Member checking (see appendix 3.5 (a)), which took place during the second interview, ensured that my initial interpretation of data was in keeping with their ‘truth’. Interpretation of participant’s data by ‘re-storying stories’ followed the principles outlined by McCormack[323] and Ollerenshaw et al,[324] within the NA framework set out by Polkinghorne.[291] This NA focused on actions and events described by the participant to generate their story, rather than ‘analysis of narrative’ creating their story. The research methods section 3.6 demonstrates the re-storying principles used in my interpretation and analysis of participant’s narrative interview data,[244, 313, 323, 324] and as further detailed in appendix 3.6.

3.4 Ethical considerations

Research participant narrative data, to be used in the academic community, had many ethical considerations such as anonymity for the participant and true representation of their lived experience. This entailed accurate channelling of their lived experiences into academic form, by working with them as their ally reflecting their literal spoken words and intent rather than deciphering and interpreting their meaning. Due to the relationality of NA, I had to consider my ethical duty, practice and code.[304] In depth ethical considerations were accounted for and are detailed in appendix 3.7. Ethical approval for the narrative study was awarded by the Research Ethics Committee, College of Human and Health Sciences, Swansea University, Singleton Park, Swansea, SA2 8PP, South Wales, U.K. The research adhered to the University's ethical code of practice and it was approved in accordance with their criteria. I adhered to data protection laws, confidentiality, and storage of personal data.

3.5 Quality

Qualitative researchers disagree on the criteria used to assess the quality of a research study.[330] Many researchers argue against the application of a standardized assessment on the quality of qualitative research,[330, 331] particularly when narrative in nature, due to the wide variety of methodological approaches used by such researchers. They state that core to a narrative is flexibility so that participants are able to tell their story without the impediment that standardisation would bring. I adopted the naturalistic criteria developed by Lincoln et al[250] in this research as well as the recommendations made by O'Brien et al[310] in their Standards for reporting qualitative research, which I used as a guide when appraising, applying, and synthesizing the study findings. The COREQ framework was also used.[305] For further details on the quality criterion included in this research see appendix 3.8.

3.6 Research methods

3.6.1 Purposeful sampling and target number

This narrative research used a purposeful sampling strategy in which individuals were selected to share their experiences transitioning throughout education. The target number of university and/or post-university individuals in the research was set at between 5-15 research participants. This number was in line with an average for other narrative reviews in either the same or similar research fields (narrative literature reviewed as of 8/2/19).[332-335] Using a representative sample group enabled me to apply participants' data, in the context of current evidence-based literature, to the wider population in question.

3.6.2 Inclusion criteria and exclusion criteria

A summary of the inclusion/exclusion criteria used to recruit participants and their parental figures for interviews is shown in table 3.2. Crucial to the research question were individuals who had a medical diagnosis of autism spectrum disorder (ASD), as verified by me in my professional role as an autism practitioner, and who were either currently in university or had attended university (with or without successful completion of study). To broaden data retrieval, they could be of any gender and could have attended any university in the UK. The participants were aged between 18-26 years. This age range was believed to be representative of the individual with autism population who were currently in or had recently attended university. The upper age limit of 26 years was used based on estimated figures, to account for the fact that individuals can take longer to complete secondary and/or further education (estimate of two extra years), and/or may need to retake years at university (estimate of two extra years) (estimates based on my professional experience). The interviews were conducted through the medium of English which meant that non-English speakers were excluded from the study. The 'parental figure' was parents or carers who had been involved in the participants life throughout their educational journey and who were able to converse in English.

Table 3.2: Summary of the inclusion/exclusion criteria for participants and their parental figure.

Participant	
Inclusion criteria	**Exclusion criteria**
Medical diagnosis of ASD	Non-English speaker
Recently attended or currently attending university	Not diagnosed with ASD
Between 18-26 years old	
Parental figure	
Inclusion criteria	**Exclusion criteria**
Carers involved through the participant journey	Non-English speaker

3.6.3 Recruitment and selection

Individuals at university or who had attended university, were recruited through the autism spectrum condition (ASC) service, local autism social groups and word of mouth within the autism sector through an introductory cover letter. Individuals interested in being part of the research emailed me, I then checked that they met the inclusion criteria, and those who did were sent all the ethically approved information needed to proceed (see section 3.4 and appendix 3.7).

3.6.4 Setting/site and salient contextual factors

Research participants who were currently attending university were interviewed on their university campus, in a private and familiar location. Participants who were no longer attending university or who were only available during the holiday period were interviewed in a private room in their homes. Refreshments were made available for both parties to encourage a sense of informality. Parental figure interviews also took place in a private room in their homes or, when this was not possible due to time and travel constraints, over the telephone.

3.6.5 The narrative interview process and data collection methods

3.6.5.1 Design of narrative interview framework and prompts and test interview

I implemented procedures that aimed to enable participants to fully express their lived experience story, through a narrative interview framework. The framework was planned in detail prior to the interview(s) to account for key literature findings, to ensure appropriate data was recorded through schema notes and reflective diary entries and to prepare instrumental needs such as audio recording equipment.

Prior to starting the narrative interviews, I conducted a test interview with a pilot participant who met the inclusion criteria, as detailed in appendix 3.9. The aim of this was to refine the narrative interview framework and prompts, and to gain insight into how the participant could potentially respond during their interview. Following the test interview minor changes to the narrative interview framework and prompts were made, this was then used throughout all participant interviews.

3.6.5.2 Audio transcription

Audio recordings were used to gather all interview data. After each interview, data was sent to an external transcription service for transcription. Upon receipt of a raw transcript from the service, I assessed it for accuracy via the methods outlined in the narrative interview section below (3.6.5.4).

3.6.5.3 Schema Notes (Sjuzet and Fabula) and Reflective Diary Entries

I collected participant's non-verbal data during every interview phase through schema notes, or Sjuzet and Fabula entries, and reflective diary entries (which were made post-interview), any additional sjuzet and fabula entries were also added post-interview. Sjuzet notes detailed the plot in which the narrative was told, how the research participant told their story, their intonation, tone of voice, over emphasising, body language, and so on. Fabula notes detailed the content of the participant's story, such as key occurring events that were often retold by the participant, represented via direct quotes taken from the individual transcripts.

3.6.5.4 Narrative interview

Data was collected through the medium of narrative interviews and data collection steps followed as outlined in figure 3.7. In **participant interview one** I collected data using a narrative interview framework and prompts mind map to guide the interview (appendix 3.10). Audio recordings were made and non-verbal data collected through schema notes and reflective diary entries. Post-interview one the audio recordings were uploaded to an external transcription service and returned as raw transcribed data. I assessed the raw transcript, for accuracy and any transcription errors were highlighted to and corrected by the transcription agency. The updated transcript was re-checked for accuracy. I then added my schema notes and reflective diary entries to the transcript creating the combined transcript from interview one. From this transcript I wrote a summary of findings for use in interview two (member checking).

In **participant interview two** (member checking) the participant was invited back to review the summary of findings from interview one for accuracy. Any corrections given by them and any additional information supplied was noted. Once again, audio recordings were made during the interview and schema notes/reflective diary entries written. Post-interview transcripts were created and checked for accuracy using the methods described for interview one. I then added the participant corrections and any additional relevant information raised, with its accompanying schema notes/reflective diary entries, to the combined transcript from interview one to form an updated combined transcript.

In the **parental figure(s) interview** data of relevance to the participant’s story was collected using a narrative interview framework and prompts to guide the interview. As in other interviews, audio recordings were made during the interview and schema notes/reflective diary entries written. Post-interview transcripts were created and checked for accuracy using the methods described for interview one. I then added any relevant information raised by parental figure(s), with its schema notes/reflective diary entries, to the updated combined transcript from interview two to form a final transcript.

For each participant, their final transcript was then used in the re-storying and analytical process.

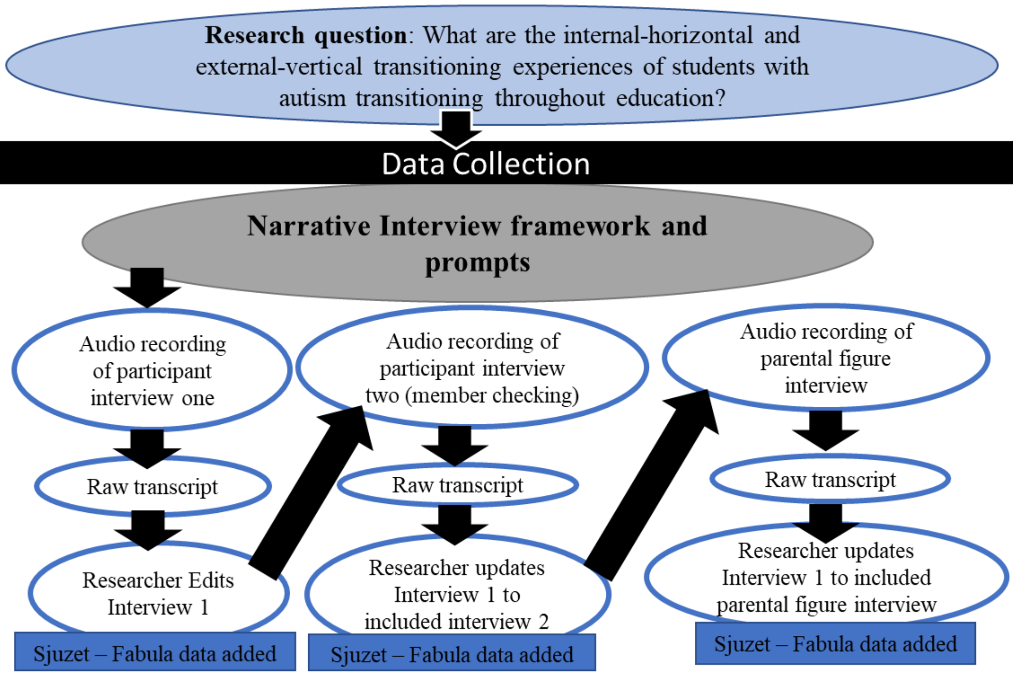


Figure 3.7: Data Collection of individual participant cases.

3.6.6 Data interpretation and analysis

Final narrative transcripts were analysed using a data coding criteria (appendix 3.11) and the procedure steps outlined in figure 3.8. Initially, I used the stepwise combination of holistic-content analysis (HCA), categorical-content analysis (CCA), categorical-form analysis (CFA) and complete holistic-form analysis (HFA) as illustrated in figure 3.8 (steps 1-4). These results were further analysed, and interpretated (step 5) through use of the educational transitioning model (previous outlined, see figure 3.6) to detail the participant’s ability to adapt to each core transitioning theme (CTT). Finally, in step 6, I critically analysed the complete narrative to consider the functionality of a participant’s narrative, how they positioned them self within it as well as any critical positioning theme that might be suggested.

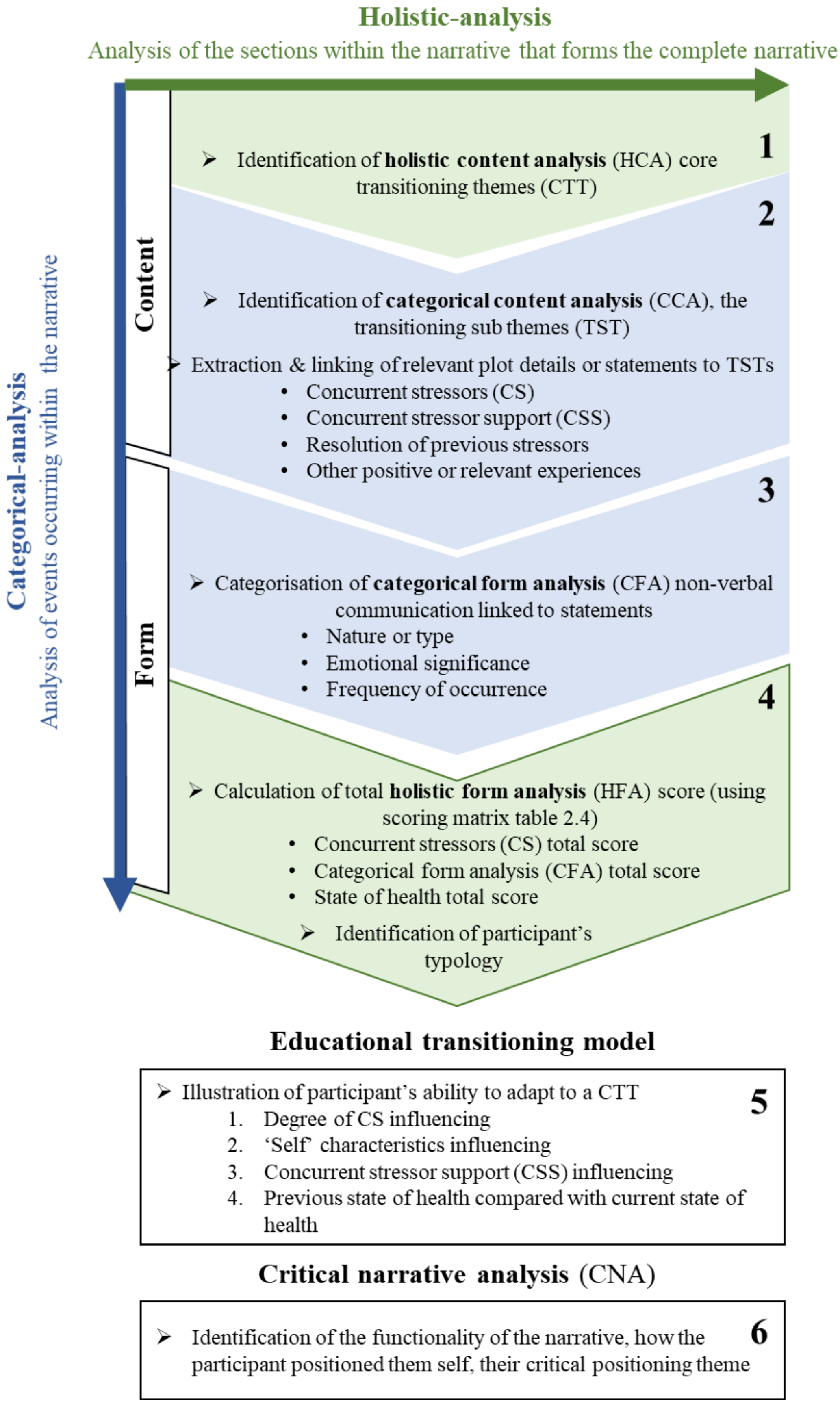


Figure 3.8: Procedural steps. Data interpretation and analysis methods (steps 1-4), illustration through the educational transitioning model (step 5), and critical narrative analysis (step 6), implemented in research. CCA = categorical-content analysis, CFA = categorical-form analysis, HCA = holistic-content analysis, HFA = holistic-form analysis, CNA = critical narrative analysis, CTT = core transitioning themes, TST = transitioning subthemes, CS = concurrent stressors, CSS = concurrent stressor support.

3.6.6.1 Procedural steps 1-2

Holistic-content analysis (HCA; figure 3.8 step 1) was performed on the final narrative transcript to identify the core transition themes (CTT) (these were the various educational phases or schools/college attended and mapped through time or age). HCA data consisted of life changing events within the CTT, the participant's perspectives about their experiences, them self and their social fit. Categorical-content analysis (CCA; figure 3.8 step 2) was performed on the final narrative transcript to identify the transition subthemes (TST), or the major categories that the content/nature of the narrative could be grouped under, that occurred throughout the participants educational journey. Both HCA and CCA data was made up from participant quotes, which were analysed and investigated for narrative features through its fabula (transcribed narrative) content, as well as related schema and reflective diary entries.

CCA data was added to each TST, within each point in the educational journey or CTT, by identifying relevant statements or plot details (epiphanies, characters, settings, problems arising, actions occurring, resolutions, turning points, personal and social interactions, time factors (past, present, future)) that made-up the narrative. Relevant statements included, but were not limited to, those related to educational events or experiences told that caused or potentially had caused stress to the participant, otherwise known as concurrent stressors (CS). Evidence of good support practice that was aimed at supporting the participant in the educational setting, otherwise known as concurrent stressor support (CSS), as well as demonstrations of resolutions of a previous stressor or demonstrations of a positive experience linked to the educational setting, were also included.

3.6.6.2 Procedural step 3

The relevant statements identified in the content analysis were subjected to categorical-form analysis (CFA; figure 3.8 step 3). This was performed by using the fabula notes and tagging frequency of nonverbal occurrences within the narrative. Nonverbal data was retrieved from reflective diary entries based on unfocused open listening techniques, observations of participant's tone of voice, body language, intonation, as well as writing notes on meta statements when participants reflected on their self-belief, self-concept, the logic of the narrative, when moral statements were made and/or inner dialogues were observed. All CFA data was then categorised and frequencies calculated. CFA data that related to state of health, positive and negative, was then used to illustrate tonal frequency within the narrative.

3.6.6.3 Procedural step 4

In order to perform the holistic-form analysis (HFA; figure 3.8 step 4) stage of the process I had to design a scoring matrix that could attribute values that reflected the relative impact of the experience on the participant during a CTT (table 3.3). The score for a CTT, was calculated by combining value scores to (i) identified CS during the CTT (using the HCA and CCA results), e.g., major Ac-CS (impacting state of health), minor ES-CS, or major ES-CS, (ii) CFA linguistic results, which were categorised as major or minor during the CTT, (iii) participant's state of health during the CTT, which was categorised as a major or a minor deterioration or improvement.

The HFA CTT score was then compared with the previous CTT score to formally considering the overall structure of the narrative and how the participant positioned them self within each CTT. Focusing on the participant's typology, cohesion within the narrative and turning points, as well as how the narrative progressed (e.g., when the HFA CTT score was positive, how this reflected positive experiences) or regressed (e.g., when the HFA CTT score was negative, how this reflected negative experiences).

The limitations of using a scoring matrix are discussed in section 6.7.

Table 3.3: Holistic-form analysis (HFA) scoring matrix. HFA score: Calculated by adding together relevant HCA, CCA, CFA variables from a participant's CTT to produce an HFA numerical score that is attributed to a CTT. This score can then be compared with another CTT to gauge participant's narrative progression or regression. For abbreviations see table 3.4.

HFA scoring matrix (using HCA, CCA, CFA data)		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results) for current CTT		
Minor Ac-CS	An individual Ac-CS that occurred during the current CTT that negatively impacted the participant academically (without resulting in ES-CS).	**n = 0**
Major Ac-CS (impacting state of health)	An individual Ac-CS that occurred during the current CTT that negatively impacted the participant academically and resulted in ES-CS during the current CTT.	**n = -5**
Minor ES-CS	An individual ES-CS that occurred during the current CTT that negatively impacted the participant and resulted in ongoing minor ES-CS during the current CTT e.g., '**anxiety about how to make new friends**' (S).	**n = -5**
Major ES-CS	An ongoing ES-CS that occurred during the current and other CTTs that negatively impacted the participant and resulted in ongoing major ES-CS during the current CTT e.g., '**being undiagnosed ASC**' (P/S/6), '**being bullied**' (S/6).	**n = -10**
(ii) CFA linguistic results (categorising stressors) for current CTT		
Minor negative CFA tone	The greatest occurrence of a tone when discussing the current CTT (compared with other CTTs) that is suggestive of a negative experience e.g., greatest occurrence overall of 'withdrawing' when referring to primary experiences	**n = -25**
Major negative CFA tone	The greatest occurrence of negative CCA tone when discussing the current CTT (compared with other CTTs) e.g., the greatest occurrence overall of sad tones when referring to primary experiences.	**n = -50**
Minor positive CFA tone	The greatest occurrence of a tone when discussing the current CTT (compared with other CTTs) that is suggestive of a positive experience e.g., greatest occurrence overall of 'smiling' when referring to primary experiences.	**n = +25**
Major positive CFA tone	The greatest occurrence of positive CCA tone when discussing the current CTT (compared with other CTTs) e.g., the greatest occurrence of happy tones when referring to primary experiences	**n = +50**
(iii) State of health for current CTT		
Minor deterioration in state of health (MiD)	The total of ES-CS that occurred in the previous CTT minus the total of ES-CS that occurred in the current CTT. A MiD occurs if the participant has a minor increase in ES-CS overall.	**n = -50**
Major deterioration in state of health (MaD)	The total of ES-CS that occurred in the previous CTT minus the total of ES-CS that occurred in the current CTT. A MaD occurs if the participant has a major increase in ES-CS overall.	**n = -100**
Minor improvement in state of health (MiI)	The total of ES-CS that occurred in the previous CTT minus the total of ES-CS that occurred in current CTT. A MiI occurs if the participant has a minor reduction in ES-CS overall.	**n = +50**
Major improvement in state of health (MaI)	The total of ES-CS that occurred in the previous CTT minus the total of ES-CS that occurred in current CTT. A MaI occurs if the participant has a major reduction in ES-CS overall.	**n = +100**
		TOTAL Holistic-form analysis SCORE

3.6.6.4 Procedural step 5

To be able to illustrate the participant's characteristics of transitioning experiences, how they adapted to each transition, I combined participant's HCA, CCA, CFA, HFA findings in relation to each CTT, into the **educational transitioning model** (figure 3.8 step 5 and 3.9). This model encompassed the models outlined in section 3.2.3 and 3.3.3, primarily the 'educational transitioning model' (figure 3.6), adapted from Schlossberg[266-268] transitioning model, with elemental features taken from Bronfenbrenner's Bio-ecological and PPCT model.[255, 256] Findings also took into account, when relevant to do so, the models of Maslow,[257-259] Ellaway et al,[263] MacGill[264] and Prochaska et al,[265] outlined in section 3.2.3 and 3.3.3.

The model was used as a framework in which to summarise a participant's lived experiences and transitioning journey, for each CTT where analysed data was extracted and applied within the model. This included (1) data representing the participant's perception of CS experiences during the CTT, (2) inclusion of participant's 'self' characteristics during the CTT, e.g., if undiagnosed, self-advocacy skills, resilience, and if data is available what impact this might have had, (3) inclusion of CSS data and how this influenced the participant's ability to adapt and (4) the combination of the aforementioned data to produce a summary of participant's ability to adapt during the CTT. This was done by comparing degree of CS impacting state of health from previous CTT to current CTT (CS impacting state of health) and by providing a concluding statement as to participant's overall state of health during the current CTT, whether this has majorly improved or declined, minorly improved or declined, with supporting evidence to justify this finding.

As mentioned earlier (section 3.3.3.7), it should be noted that an in-depth investigation of personal characteristics and psychological resources did not take place in this research, with the exception of the inclusion of undiagnosed conditions and/or data shared by participants in the context of their educational transitioning journey, as I felt that this went beyond the scope of this PhD (see figure 3.9, box 2, highlighted in grey).

Table 3.4: Educational transitioning model abbreviations.

Educational transitioning model abbreviations	
Description	**Abbreviation**
Concurrent stressor support	**CSS**
Concurrent stressor(s) e.g., bullying	**CS**
Core transitioning theme	**CTT**
e.g., primary	**P**
e.g., secondary	**S**
e.g., sixth form	**6**
e.g., University	**U**
e.g., University BSc	**UBSc**
e.g., University MSc	**UMSc**
Efficacy of concurrent stressor support	**ECSS**
Major deterioration in state of health e.g., due to major increase in CS	**MaD**
Major improvement in state of health e.g., due to major decrease in CS	**MaI**
Minor deterioration in state of health e.g., due to minor increase in CS	**MiD**
Minor improvement in state of health e.g., due to minor decrease in CS	**MiI**
Transitioning subtheme e.g., emotional-social	**TST**

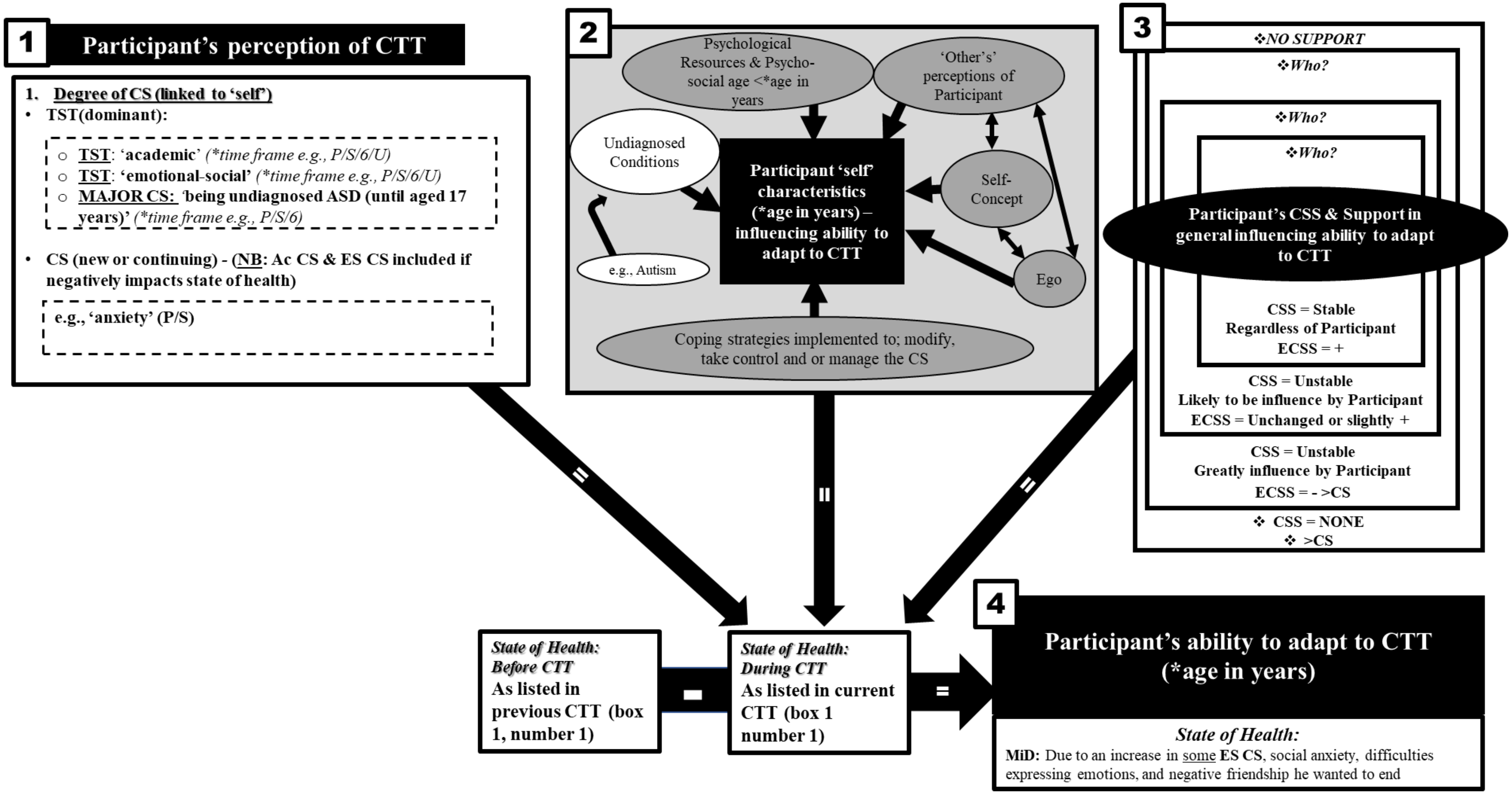


Figure 3.9: Educational transitioning model representing participants (with autism) ability to adapt to a core transitioning theme. Adapted from:[255-259, 263-268]
For abbreviations see chapter three, table 3.4.

3.6.6.5 Procedural step 6

Critical narrative analysis (CNA; figure 3.8 step 6) of data involved me investigating the functionality of the participant's narrative to determine how they positioned them self within (previously explored in section 3.6.6.3). This was achieved by analysing fabula and sjuzet data, as well as findings from the previous narrative analysis (NA) methods. Particular attention was paid to data that reflected participant's thoughts, feelings, emotions, actions, interactions, achievements, challenges, and the social structure in which their narrative took place. Positive experiences shared, positive skill development, such as resilience, self-advocacy, as well as interactions and the social structure, in the context of good support practice, were noted. Data was considered within the wider analytical context, particularly in conjunction with the CFA data which indicated tonal and non-verbal emotional expressions, and a critical positioning theme was then identified for each participant with exact quotes and non-verbal data used to justify my findings.

3.7 Chapter summary

A narrative analysis approach was deemed the most efficacious qualitative method in enabling individuals to express their lived experiences transitioning throughout education. Based on theoretical and philosophical underpinnings individuals were able to express their reality through an ideographic inductive first-person research strategy. Inclusion of data relating to critical theory, social constructs such as disablism, and wider social contexts were crucial due to the likelihood that these would have an influence on the individual, particularly their self-conception. A naturalistic idealist interviewing method was considered most appropriate, from a constructive subjective perspective, with the researcher-participant relationship being collaborative, unbounded, and without distance. Any potential for bias was counterbalanced through a demonstration of researcher reflexivity, reflection, quality criterion, transparency, and adhering to ethical considerations. Data collection methods reflected theoretical considerations, my (the researchers) dual role as reflective transcriber, as well as the importance of schema notes, and reflective diary entries, in recording non-verbals. Data interpretation and analysis procedural steps were followed including holistic-content analysis, categorical-content analysis, holistic-form analysis, categorical-form analysis, and critical narrative analysis methods.

The methodology and methods in this research have enabled me to collect, interpret, and analyse, participant data, which is not generalisable, however which is transferable to the universal transitioning experiences faced by individuals with autism. This approach makes it possible to, post-completion of the thesis, produce a guide: ‘Educational transitions. A guide to best practice: Supporting neuro-diverse students’ transitions into a new educational phase and with their day-to-day needs’. This guide is intended for educational support providers, illustrating potential barriers, differences and difficulties facing individuals (with autism and related neuro-diverse conditions), on their educational journey, the support needs that they might have, and to contribute towards improving the lived experiences of an individual. I am also able to produce two resources intended for neuro-diverse students (their families): (1) ‘Preparing for secondary school or sixth form: Managing your transition into a new educational phase and your day-to-day needs’ and (2) ‘Preparing for university: Managing your transition into university and your day-to-day needs’.

Chapter 4: Narrative results

4.1 Chapter Overview

Key to this narrative research study was ensuring that each individual research participant was given the opportunity to tell their story, about their unique experiences transitioning throughout education. I was mindful of the fact that academics reading research studies are often quick to move on to the studies reported findings and hence I stress that to truly understand the educational transitioning experiences of individuals (with autism) it is imperative to read the complete PhD study. Readers will see that the holistic-content analysis (HCA) and categorical-content analysis (CCA) approaches taken have resulted in detailed accounts given by each participant, as well as the Sjuzet and Fabula considerations, these accounts will enable the reader to gain compendious insight into participants' unique experiences. Procedural steps will be discussed throughout this chapter and detailed information on these is available in chapter 3, figure 3.8.

4.2 Participants in the Narrative Study

Six participants were recruited for the narrative study and took part in interview one. Table 4 (a) represents the number of participants, their parental figures and identification labels assigned to them. However, the final number of participants was reduced to five as the result of participant John being excluded from the research study. Following interview one, John did not respond to my invitation to attend interview two, resulting in lack of data verification by the participant via member checking. Also, it was not possible to use parental figure interview data in the context of Mark's analysis due to inappropriate information being shared which was not relevant to the purpose of the research.

Table 4 (a): Anonymised coding/names assigned to the study participants and their parental figures. *data was excluded from the study (shaded light grey); PFM = parental figure mum; PFD = parental figure dad.

	Participant					
	1	**2**	**3**	**4**	**5**	***6**
Participant code number	P201	P202	P203	P204	P205	P206
Anonymised name	Mark	Karen	Jane	Leigh	Andy	John
Parental figure code number	*n/a	PFM202	PFM203	PFM204	PFM205	n/a
Anonymised name		Mum	Mum	Mum	Mum	
Parental figure code number	-	-	-	PFD204	-	-
Anonymised name				Dad		

4.3 Abbreviations and textual highlight coding

The abbreviations that are used throughout the results chapter are outlined in table 4 (b). Within the main body of the text, tables, and figures: (1) Concurrent stressors (CS) are identified by being written in bold within single inverted commas. These can appear in the text as either specific stressors that related to one particular stress trigger mentioned within the course of the narrative (e.g., '**confusion about behaving differently to his peers**') or the generic group of stressors to which the specific stressors belong (e.g., the aforementioned specific stressor could be assigned to a '**social confusion**' CS group). (2) Direct quotes from the narrative are shown in italics surrounded by double inverted commas. (3) Support received for the CS, otherwise known as concurrent stressor support (CSS), is highlighted within a dashed-boxed area with the CSS shown in italicised bold within single inverted commas.

Table 4 (b): Chapter four abbreviations.

Description	Abbreviation
Concurrent stressor support	**CSS**
Concurrent stressor(s)	**CS**
Academic	**Ac**
Emotional-social	**ES**
Emotional-social transitioning	**EST**
Undiagnosed (with autism)	**Un**
Core transitioning theme	**CTT**
primary	**P**
secondary	**S**
sixth form	**6**
university	**U**
university BSc	**UBSc**
university MSc	**UMSc**
Efficacy of concurrent stressor support	**ECSS**
Narrative analysis (methods)	**NA**
Categorical-content analysis	**CCA**
Categorical-form analysis	**CFA**
Critical narrative analysis	**CNA**
Holistic-content analysis	**HCA**
Holistic-form analysis	**HFA**
Major deterioration in state of health	**MaD**
Major improvement in state of health	**MaI**
Minor deterioration in state of health	**MiD**
Minor improvement in state of health	**MiI**
Parental figure dad	**PFD**
Parental figure mum	**PFM**
Sensory challenges	**SnC**
Transitioning subtheme	**TST**

4.4 Mark’s story

4.4.1 Background and setting

The initial participant interview with Mark took place in his current university in a private lounge area. At the time of the interview, Mark was in the second year of his history degree.

4.4.2 Procedural steps 1-2: Overview

The holistic-content analysis (HCA) of Mark’s data is reflected in table 4.1 (a), the core transitioning themes (CTT) that emerged from his educational journey narrative. Two overarching TSTs were identified, namely ‘**academic**’ (Ac) and ‘**emotional-social**’ (ES). The ‘**emotional-social**’ (ES) subtheme has been grouped to include CS related to this heading such as; bullying, discrimination, friendship, group interactions, mental health (e.g., anxiety, fears, phobias, self-harm, stress), social anxiety, stigma, and so on. Please note, the first and second primary CTT have been merged as all information shared by Mark crossed over into both of these CTTs.

Table 4.1 (a): Holistic-content analysis overview: Mark’s core transitioning themes (CTT) and transitioning sub-themes (TST). His age during each CTT is indicated within the brackets.

<table>
<tr><th colspan="5">Core transitioning themes (CTT)</th></tr>
<tr><th></th><th>1st Primary School (4-6 years)
2nd Primary school (6-11 years)</th><th>Secondary School (11-16 years)</th><th>Sixth form (16-18 years)</th><th>University (BSc) (18-21 years)</th></tr>
<tr><th>Transitioning sub-themes (TST)</th><td colspan="4">Academic (Ac)
Emotional-Social (ES)</td></tr>
</table>

The categorical-content analysis (CCA) of Mark’s data, enabled a more in-depth examination of each CTT to look for patterns. For each CTT, Mark’s narrative was examined for the appearance of the specific concurrent stressors (CS) experienced by him (table 4.1 (b)) with the sections that follow giving context and describing them in detail. In the primary, secondary and sixth form CTTs their appearance appears to be exacerbated by the overarching or major ES-CS ‘**being undiagnosed ASC**’ which was likely to have had impacts on both the ‘**academic**’ (Ac) CS and ‘**emotional-social**’ (ES) CS.

Table 4.1 (b): Categorical-content analysis overview: Mark’s transitioning sub-themes (TST) and concurrent stressors (CS). Table also shows the core transitioning themes (CTT) or timepoints where the CS occurred. P = primary, S = secondary, 6 = sixth form, U = undergraduate university

Transitioning sub-themes (TST)	**Concurrent stressors (CS)**	**Time point(s)**			
		P	**S**	**6**	**U**
	Major CS: ‘being undiagnosed ASC’ (until aged 17 years) **(Un)**	**P**	**S**	**6**	
‘academic’ (Ac)					
	‘A-level essay format’			**6**	
	‘being easily distracted’				**U**
	‘being forced to spontaneous do creative writing’	**P**			
	‘being self-disciplined’				**U**
	‘creative writing’		**S**		
	‘difficulties condensing his ideas & thoughts into a rigid time frame’		**S**		
	‘difficulties with organisation and staying on track’				**U**
	‘difficulties writing legibly’	**P**			
	‘English’	**P**			
	‘extremely slow handwriting due to having to write perfectly’		**S**		
	‘his academic writing style’				**U**
	‘mental arithmetic’	**P**			
	‘no reasonable adjustments in place for A-level exams initially due to being unwilling to discuss his diagnosis’			**6**	
	‘tending to procrastinate’				**U**
	‘too much historical information to remember’			**6**	
‘emotional-social’ (ES)					
	‘anxiety about speaking to people on a one-to-one basis due to the intimate personal nature of it’		**S**		
	‘apprehensive disclosing (his) autism diagnosis’				**U**
	‘being bullied due to being naïve’		**S**		
	‘being stuck in a negative friendship he wanted to end’	**P**			
	‘being surrounded by emotionally expressive people’				**U**
	‘confusion about behaving differently to his peers’		**S**		
	‘confusion and social frustration during his puberty years’		**S**		
	‘didn’t have friends or anyone to confide in’	**P**			
	‘difficulties accepting change’	**P**			
	‘difficulties maintaining a regular sleep cycle’				**U**
	‘difficulties going to nightclubs because he was then unable to talk to his peers’				**U**
	‘difficulties with the social aspects of beavers and cubs’	**P**			
	‘difficulty fitting in with his peers and their “mafia mentality”‘		**S**		
	‘fear of failing academically at university’				**U**
	‘inability to express his emotions due to upbringing’	**P**	**S**	**6**	
	‘lack of educational referral for assessment’	**P**	**S**		
	‘making a big social leap’		**S**		
	‘not having anyone at school he could talk to about emotional difficulties’		**S**		
	‘not knowing the protocol around others who are being passionate and loving towards each other’				**U**
	‘peers questioning him as to why he was in a smaller room for exams’		**S**		
	‘stigma about being autistic and worrying about his peer’s reaction to this’		**S**	**6**	
	‘struggling socially’	**P**			
	‘suffering indirect homophobia from peers’		**S**		
‘emotional-social transition’ (EST)					
	‘anxiety about so much change’		**S**		
	‘anxiety about how to make new friends’		**S**		
	‘anxiety about what to expect in new school’		**S**		
	‘having to meet a whole load of new people’				**U**
	‘having to visit other universities with his parents even though he had ‘already decided due to his chosen universities autistic CSS’				**U**
	‘lack of explicit instructions on how to interact and communicate with peers’		**S**		
	‘living independently’				**U**
	‘not being able to tell parents that he wanted to go to his chosen ‘university due to its autistic CSS’				**U**
	‘the uncertainty ahead of him’				**U**
	‘worried about being rejected by his peers and that no one would like him’				**U**

4.4.3 Procedural steps 1-2: Primary CTT

4.4.3.1 Academic concurrent stressors (Ac-CS)

Mark stated that he experienced CSs in '**English**' and '**mental arithmetic**'.

> "*I definitely struggled with English definitely. Math I've never really liked…* (chuckles)*… Numbers just do not get on with me. I especially remember struggling with mental arithmetic stuff. I hated that stuff… I definitely struggled with was creative writing which is kind of ironic because I tend to sometimes like to write stories nowadays but being stuck in a classroom and basically sit down, here's a piece of paper, you got an hour and a half, write me a story now, like I hated that*".(P201/00:23:55)

He factually shared that he had problems with his handwriting which resulted in '**difficulties writing legibly**'.

> "*…my handwriting in primary school was really bad… It was like I suppose it was legible, but it wasn't that great*".(P201/00:41:35)

Ac-CSS

He wasn't aware of receiving any Ac-CSS.

> "*I think there may well have been teaching assistants, but I was not on their radar*".(P201/00:24:51)

4.4.3.2 Emotional-social concurrent stressors (ES-CS)

Hesitantly, Mark shared that he had a particularly negative friendship during primary school that he was unable to remove himself from which resulted in him '**being stuck in a negative friendship he wanted to end**'. At the time he stated that he did not "*... really want to go against him because I don't want to be on his wrath and also piss him off because I have this kind of non-aggression sort of mindset of, 'I don't want to annoy anyone'. So, I definitely found that a bit of a shock*".(P201/00:21·50)

Factually, Mark shared that he had "*acquaintances*", not "*friends*", resulting in a CS because he '**didn't have friends or anyone to confide in**'.

> "*I didn't really have any friends in primary school thinking back… I had acquaintances. I knew most of the people in the school and I didn't have any issues with anyone, but I mean looking back I didn't have any friends, like there wasn't anyone I could really confide in … although I knew all the kids at the school I wouldn't see them usually outside of the school because I lived six miles away and plus I was a heavily autistic kid so I'd just be sitting in doors all day just wanting to sit around playing with toys. I wouldn't want to be going interacting with the kids, like no*".(P201/00:22:19)

He appeared despondent sharing that he found social play difficult, especially the ever-changing nature of it and that this resulted in '**difficulties accepting change**'.

> "*Vaguely I remember you do a lot of pretend acting when you're in primary school like, 'Let's pretend with this', et cetera, et cetera, and then they would change it around and say, 'Oh no, we're going to do this now'. My autistic brain was like, 'No, but we're doing this. Let's continue doing this,' and they were like, 'No, no, we're changing it now,' and my brain was like misfunctioning*".(P201/00:19:05)

Mark's body language withdrew as he described, using a despondent tone, that he was closed off emotionally or had an '**inability to express his emotions**' during this CTT. He believed this stressor resulted from his up bringing.

> "*I think it's simply because I have become quite emotionally callous… emotionally closed off. So, my family don't express emotion… in primary school I was very emotionally callous in the sense that if someone asked how I was feeling about anything it was just the same answer, 'Yeah, fine. Why would I talk to you about my emotions?' … It's very difficult if you're a child to even contemplate being emotional if you're being raised in a household where emotional expression isn't talked about let alone accepted*".(P201/00:25:59)

Socially, Mark expressed, using a sad tone, that he had difficulties interacting with his peers, that his peers may have thought he was doing 'weird' things, and this resulted in him '**struggling socially**'.

> "*I definitely remember not always necessarily interacting well with other kids… looking back now I can tell that what they thought I was doing was weird or like if I was taking something literally or if I was doing something, they thought was a bit odd*".(P201/00:18:34)

Although Mark attended activities outside of school during this CTT, namely beavers and cubs, he also expressed that he had '**difficulties with the social aspects of beavers and cubs**' and did not like going to these due to not wanting to socially interact with his peers.

> "*… beavers and cubs … I didn't like because it was another social thing outside of the school… you're throwing me into a situation where I'm surrounded by a whole load of kids most of which I know but it's another social event some of which I don't know but to have to do all these activities I don't particularly want. I don't like this, and so I would always try to get out of it when I could, and that persisted through secondary school as well*".(P201/00:23:08)

ES-CSS (Evidence of good support practice)

Mark was provided with ES-CSS from his '***Mum***' and '***private tutor***', whose support started during his last two years of primary school, "*beginning in year five*".(P201/00:01:33) He also appeared to received ES-CSS from a '***small group of peers'***.

4.4.4 Procedural steps 1-2: Secondary CTT

4.4.4.1 Emotional-social transitioning concurrent stressors (EST-CS)

Prior to making the vertical transition into secondary school, Mark expressed ‘**anxiety about how to make new friends**’ and ‘**anxiety about so much change**’.

> “*…that I didn’t know anyone. How would I interact with everyone? I’m going to have to make all these new friendships or interact with all these new people… …this is so much change*”.(P201/00:39:33)

Hesitantly, he shared that he was excited about going but this was combined with social anxiety, and that this resulted in his ‘**anxiety about what to expect in new school**’.

> “*Excitement at the thought that I’m going to this big bold place now… but at the same time there was this sort of I don’t know anyone there. What the hell is going to happen once…* (pause)…? *No idea. Yeah, it was very, very odd*”.(P201/00:39:13)

He expressed, in a serious tone, how he was asked to do an ‘icebreaker’ session with his peers during a transition day which resulted in a CS that arose due to a ‘**lack of explicit instructions on how to interact and communicate with peers**’.

> “*...that was interesting because once again obviously not knowing I was autistic we had to do an icebreaker session. Everyone sat down with another random person from the ... to get to know them. I’m like, ‘Get to know them?’ ... I’m like, ‘Give me a set of instructions. I’ll go through that happily but you’re telling me to improvise?’ ...*”.(P201/00:35·04)

<u>EST-CSS</u> (Evidence of good support practice)

Mark factually described EST-CSS from a ‘***secondary school transition event***’ that he attended at his secondary school prior to starting there, how being introduced to his form class was helpful and how through this introduction he formed some good friendships.

> "*…once I've been accepted to* 'The school' *I then had an induction session where I met my form class for the first time which is then where I met my very good friend* 'J' *who I'm still friends with back home… I also met* 'H' *there*".(P201/00:34:30)

4.4.4.2 Academic concurrent stressors (Ac-CS)

At the beginning of Mark's secondary CTT, he was placed in the lower sets for most academic subjects. In a factual manner he described experiencing Ac-CS in '**creative writing**' and '**difficulties condensing his ideas & thoughts into a rigid time frame**'.

> "*When I came in year seven, I was in usually lower sets … for most things and as I progressively got through secondary school, I started to rise through … with* 'private tutor's' *help… creative writing was a struggle on my brain. In year seven I have to do a creative writing piece… I remember sitting there going, 'Okay, fine. I've got this entire sort of story in my head. I've now got an hour and a half. I can't write it all down. You're going to tell me that I'm going to have to write an extract of this, but I don't want to write an extract of this. I want to write the whole thing down' … I think I just ended up writing down part of the story until I ran out of time, but I couldn't really end it well because I was having to artificially end it before I wanted to so that was kind of a struggle*".(P201/00:40:20)

Handwriting illegibility during Mark's primary CTT appeared to transform into a new Ac-CS during his secondary CTT when he became a 'perfectionist', producing written work that had to be perfect and neat, resulting in '**extremely slow handwriting due to having to write perfectly**'.

> "*My handwriting … by the time I got into secondary school it became like… really neat … to the point where it was recognised for girl's handwriting kind of neat … The problem is I found out it took me absolutely forever to write anything down … most of the kids then speed up I couldn't because then my perfectionist kind of side of my brain was like, 'But this doesn't look right. You need to write this properly' … So that was this kind of real dilemma and to tell you what doing stuff on laptops now at uni, oh my God, typing up your exam is so much easier*".(P201/00:41:15)

Ac-CSS (Evidence of good support practice)

By the end of this secondary CTT Mark progressed into higher academic sets which he believed was due to Ac-CSS from his '***private tutor***'. Following on from '***Mum***' and his '***private tutor***' speaking to his teachers, his secondary school put '***some adjustments in place***' for his GCSE exams which took the form of a '***smaller room for exams***'. However, he stated that he was not given, "*any extra time, didn't have my stuff on laptop*".(P201/00:44:20)

4.4.4.3 Emotional-social concurrent stressors (ES-CS)

Emotionally Mark described himself as '**being bullied due to being naïve**'.

> "*I was very naive…*(laughs)*… I was very, very naive but I think the problem was is also naivety was pounced upon so for instance if some new colloquialism or euphemism, if some of the kids at school or somebody discovered some sort of naughty word almost…naivety, ignorance, emotional expression especially within lads as weaknesses and is pounced upon, you didn't want to be made fun of by the entire year… it's everything from not understanding a certain word to, I don't know, potentially having…*(pause)*… one of my friends in my form sometimes wants to meet in lunch, take my lunchbox and sort of run around the lunchroom with it to try and piss me off*".(P201/00:48:30)

Laughing he shared that he had no inclination that he was autistic until he was in secondary school when his private tutor suggested it to him. This led to him feeling '**confusion about behaving differently to his peers**' and confusion about '**being undiagnosed ASC**' .

> "*Until year five* (aged 9/10 years) *I had no sort of inclination towards the knowledge that I was autistic … I go to secondary school. In year seven* (aged 11/12 years) *I think that's generally when I started to get told by…* 'private tutor' *… introduced this kind of idea of autism to me like,* ' 'Mark', *I think you probably are autistic*'. *Obviously at first, I was like,* '*autistic?*' *I never even really heard the term. I was like,* '*Okay, cool. What does that mean?*' *She was like,* '*You know the*

> *way you… act?*' '*Yeah, what about it?*' '*Most kids don*'*t do that*'. '*Really? No, you don*'*t say*'*…*".(P201/00:01:33)

Relaxed, using a positive, expressive tone, Mark stated that he became "*a lot more*" emotionally expressive during his secondary CTT, even if this was in his internal dialogue at this stage. Mark anxiously expressed his belief that his autism intensified his emotions during puberty, particularly in relation to his difficulties understanding the complexities of social interactions, and how this triggered '**confusion and social frustration during his puberty years**'.

> "*I definitely became a lot more emotionally expressive even just internally…Once puberty hits and hormones start happening your brain automatically starts to become a lot more emotional towards stuff and especially when you start to feel hurt by anything like if people are making fun of you or if you start to understand that you don*'*t get something, all these kind of things. Yeah, definitely even just internally in and of myself I definitely became a lot more emotional… I wouldn*'*t necessarily express it but definitely in and of myself I started to become a lot more emotional just in my own internal dialogue*".(P201/00:55:48)

When asked if he had someone to talk to about his ES-CS, he replied that he would only talk to his private tutor. He mentioned that he had a good friend 'J' but that he did not want to make his friendship "*weird*" by talking to him about feelings. This led to the CS '**not having anyone at school he could talk to about emotional difficulties**'

> "*No one in our school. It*'*s literally just the private tutor. I couldn*'*t go to the teachers because I didn*'*t feel comfortable talking with the teachers about anything … Kids… I couldn*'*t talk to because emotional expression was viewed as weakness especially within sort of much more of the lad-ish friend groups and I know the kids didn*'*t care.* 'J' *to a certain degree but I didn*'*t want to make our friendship feel weird or awkward if I started to bring emotion into it*".(P201/00:57:46)

Mark factually described how an ES-CS resulted from '**making a big social leap**' into secondary school and that he experienced '**difficulty fitting in with his peers and their "mafia mentality"…**'.

> "*Secondary school was… definitely the biggest social leap I had to … learn how to interact with the kids … it's strange because I always say that it almost becomes like a mafia mentality in some ways… you can't oust on anyone else, and it becomes very sort of I don't know almost gang-related in some ways … I mean its cases of if someone misbehaved you couldn't rat them out to a teacher or anything. It's that kind of thing where it's like we're all in this together. You can't oust us out. It's us against the teacher's kind of thing*".(P201/00:46:38)

Despondently he recalled being humiliated in the playground whilst demonstrating an aikido move to his friend 'J', resulting in the CS '**suffering indirect homophobia from peers**'.

> "*I was trying to show* 'J' *one of the holds on the wrist… Basically if you hold the hand in a certain way…that makes your whole body want to twist around… so I was trying to do this to* 'J' *and then naturally some of the kids saw us and were like,* '*Oh my God, they're holding hands*' *… a bit of … indirect homophobia*".(P201/00:51:20)

Mark hesitantly shared that he initially experienced an ES-CS when having to do public speaking in secondary CTT but described how this changed to an '**anxiety about speaking to people on a one-to-one basis**', following the moment when he realised he was more comfortable speaking publicly than talking with people individually. This he reasoned was due to the intimate nature of talking one-to-one.

> "*Public speaking when I got into the school was again difficult but then once I had that … book review moment… that's when it all switched, and I actually found that it was often actually more comfortable for me to speak in front of a whole load of people than it was one-on-one…I think because it's so much more of an intimate thing. When you're speaking one-on-one with someone it's a very sort of intimate personal thing between two people but when you're speaking in front of loads and loads of people it's very much like you're speaking almost to a brick wall at that point*".(P201/00:42:34)

'***Reasonable adjustment***' Ac-CSS was put in place for Mark which was intended to improve his academic performance. Although Mark anxiously shared that this Ac-CSS ('***smaller room for his exams***'), resulted in another two ES-CS, namely his '**peers questioning him as to why he was in a smaller room for exams**' and a '**stigma**

about being autistic and worrying about his peer's reaction to this'. Please note, Mark was not officially diagnosed with autism at this stage but appeared to accept he was on the autism spectrum and the school provided him with the necessary support.

> "*I wasn't really willing to speak about my diagnosis because I think I still was kind of worried about that kind of stigma side so I distinctly remember some of my friends would be like*, '*Why are you going to a smaller room, Mark?*' *...*". *(P201/00:44:20)*

ES-CSS CSS (Evidence of good support practice)

Throughout Mark's secondary CTT he did not receive ES-CSS for autism due to the lack of a diagnosis. Although, he would speak to his '***private tutor***' about ES-CS and appeared to receive some ES-CSS from '***Mum***', '***H***', and '***T***'.

4.4.5 Procedural steps 1-2: Sixth form CTT

4.4.5.1 The major concurrent stressor 'being undiagnosed ASC' (Un-CS)

Prior to starting sixth form Mark was not aware if the college had anything on record about his suspected autism. He continued to experience the CS '**being undiagnosed ASC**', expressing that without an official diagnosis he was unsure whether he had it or not and this resulted in him feeling unconfident about talking about it to others.

> "*As far as I'm aware nothing was on record at that point, and I was still really kind of unwilling to talk about it aside from with the private tutor … I felt comfortable talking about it with her because there was no judgement on that side, but I was still worried about judgement from I guess other people … because I hadn't had a diagnosis, I was not that confident in speaking about it because I was like I don't know if I actually do have it … which is really what the diagnosis was for… the diagnosis … there's a weight off your shoulders where it's like, 'Okay, cool'. There's no more sort of unsureness about anything. It's like, 'Okay, cool, yeah, I've got it'. Now I don't have to worry about potentially talking about it like I might have it. I do have it. Okay. Good. Move on*".(P201/01:04:51)

He also still worried people would judge him if they knew he had autism due to the '**stigma about being autistic and worrying about his peer's reaction to this**'. During the second year of the sixth form, aged 17 years, Mark was assessed and received an official autism diagnosis. He happily recalled that being diagnosed felt like "*there's a weight off your shoulders*".(P201/01:04:51)

4.4.5.2 Academic concurrent stressors (Ac-CS)

Mark, animatedly, shared that he found history fun during his sixth form CTT. Although he did struggle, explaining that there was '**too much historical information to remember**' and he found the '**A-level essay format**' difficult.

> "*History-wise that was real fun … we did the Crusades and then we did the Angevin kings … I struggled just from mainly the fact that I was having to*

> *remember so much. … and then also the fact that it didn't really click with me on how to write essays necessarily*".(P201/01:05:51)

Ac-CSS (Evidence of good support practice)
After having a diagnosis, Mark did not have Ac-CSS, additional support or reasonable adjustments put in place for exams, due to his delay disclosing.

> "*I got my diagnosis in the February of my second year so basically towards the end of college... I didn't get any help actually … It didn't help that I didn't take my diagnosis in for months because I was still unwilling to really engage… By the time I did take it in … they basically turned around and said that they couldn't do anything for me*".(P201/01:08:17)

4.4.5.3 Emotional-social concurrent stressors (ES-CS)

Although Mark expressed in his narrative that he continued to experience an '**inability to express his emotions due to upbringing**', he also shared that he experienced a major positive change emotionally-socially.

> "*Socially honestly it really wasn't that difficult primarily because most of the kids there were from* 'the previous secondary school' *so I basically had the same sort of friends* ('H' & 'T'). *I made some friends … I get a buzz from interacting with people, from talking with them*".(P201/01:11:13)

Although he admitted it was partially due to his early reticence to discuss his diagnosis, Mark had '**no reasonable adjustments in place for A-level exams**' which became a source of stress.

ES-CSS (Evidence of good support practice)
Throughout Mark's sixth form CTT he did not receive ES-CSS for autism due to the late diagnosis and refusal to disclose following his diagnosis. He continued to be provided with ES-CSS from '***mum***', '***private tutor***', '***H***', '***T***', and in addition ES-CSS from '***some new friends***'.

4.4.6 Procedural steps 1-2: University CTT

4.4.6.1 Emotional-social transitioning concurrent stressors (EST-CS)

Mark hesitantly shared that the transition from sixth form to university, to study history, was "*the most scary…*",(P201/01:13:51) educational transition and that he had felt stressed due to '**the uncertainty ahead of him**'. He had specific worries that related to '**living independently**' and '**having to meet a whole load of new people**'.

> "*Transitioning from college to uni. was definitely the most scary one… because it's so much more uncertain. Going to uni. I'm going to be living away from home… and I'm going to have to meet a whole load of new people*".(P201/01:13:51)

Although Mark then went on to proudly state, that he had "… *become a lot more socially confident…*" by the end of his sixth form which meant that during his university CTT he was "*…pretty much fine with the kind of meeting new people thing*".(P201/01:14:40). He actually went on to say later in the interview that he was most excited about, "*…meeting new people and interacting with them*". (P201/01:30:44) He did, however, also share that he '**worried about being rejected by his peers and that no one would like him**'. He said "*...rejection. Obviously, you don't want to come to uni. then have everyone not like you*".(P201/01:54:58)

Following Mark's autism diagnosis and choice of university he shared his CS as '**not being able to tell parents that he wanted to go to his chosen university due to its autistic CSS**' and '**having to visit other universities with his parents even though he had already decided due to his chosen university's autistic CSS**'. He spoke of how his choice was based on the support he could get for his autism.

> "*Basically my* 'private tutor' *took me for the first time… her daughter and son came here … so she knew the Wellbeing Services …were really good… They were both on the autism spectrum… but my parents didn't necessarily accept that … I couldn't turn around to them and say, 'mum, dad, I want to really go to* 'chosen university' *because of the fact that they care so well for the autistic people and their Wellbeing Services' … because again I couldn't talk about my diagnosis at that point. So, they were having to take me around all these other universities, and*

> *I was going around thinking, 'Yeah, this is all cool and that but nothing like* 'chosen university'*...*".(P201/01:22:41)

He confidently stated, "*as for the living away from home aspect I was also pretty fine with that because I'd always had quite a self-independent streak... I learned to cook ... I was doing that for a year or so before I even left ... for uni*".(P201/01:14:40) When he arrived at university for the first time, he was particularly excited about meeting his flatmates, "*…because I was like, 'Who am I going to meet?' because you have all these visions in your head like, 'What kind of people are going to be there?'...*".(P201/01:54:10)

<u>EST-CSS</u> (Evidence of good support practice)

Mark shared that he received EST-CSS from his sixth form prior to starting university for '***help with general administration tasks***'.

> "*…talking about the general admin side, like how do you apply to uni., this is what you do, et cetera, et cetera, and I did have support that way*".(P201/01:15:31)

Excitedly Mark recalled the first time he visited his university, aged 16 years, during a sixth form organised event. How, his university provided him with EST-CSS in the form of, an appointment with an '***autism practitioner***'. During Mark's second visit to his university, he met them again and talked excitedly about their meeting. This meeting provided Mark with EST-CSS and influenced his decision to go to his chosen university.

> "*...came and met him* (autism practitioner) *and that was like really weird to a certain extent because for the first time I was talking properly about my autism in front of someone else ... Obviously* 'he' *was lovely and immediately I was like, 'I like you. I don't necessarily know who you are, but I like you'...*".(P201/01:26·29)

As outlined in an earlier quote, another influence on this choice of university came through the support and personal recommendation of that university's autistic services from his '***private tutor***' who had arranged this second visit.

Prior to him starting, Mark's university provided him with an '***autism-specific two-day induction***', where he met fellow peers, and the '***autism practitioner***' he had met twice before. He happily went on to state that he felt for the first time that he had CSS from the specific support team. He also knew he would get '***reasonable adjustments***' for exams and teaching but at this stage he was not sure exactly what this would entail.

> "*I had the ... induction session… where they have the newbies that are coming in, the first years, before term starts everyone who's on the autistic spectrum is invited ... Two days, yeah, so we spend a day- yeah, it was one night over ... We played volleyball on the beach and everything I remember the first night… it was so much more relaxing… I think it really, really helped because I at least knew I had a safety line when I came here… I had people specifically I could go to*".(P201/01:27:29)

4.4.6.2 Academic concurrent stressors (Ac-CS)

At university, Mark expressed initial difficulties with '**his academic writing style**' and '**difficulties with organisation and staying on track**'. Mark also shared his other Ac-CS in this CTT as '**being self-disciplined**', '**being easily distracted**' and '**tending to procrastinate**'. He also had '**difficulties maintaining a regular sleep cycle**' which impacted him academically and emotionally-socially.

> "*I think the only real issue I have nowadays is self-discipline. Because I never got disciplined heavily as a child making sure that I worked hard, now at uni. suddenly I'm living by myself and having to make sure I work hard myself... I found that I have to live with an awful lot of distractions. I could procrastinate so easily*".(P201/01:37:04)

> "*I tend to be quite nocturnal… I can go into the early hours of the morning sometimes and still not feel like I'm tired, so going to bed on time for me was a huge difficulty*".(P201/01:37:58)

He stated that initially he experienced the predominant emotion of '**fear of failing academically at university**'. He believed this was "*because I didn't want to get off to a bad start, I guess*".(P201/01:55:23)

Previously, in the sixth form CTT, he had found history challenging because there were lots of facts to remember. However, at university this was not a problem, as he said "*honestly, I actually found it easier … at uni than I did at college because it's not fact-based. It's a lot more argumentative based*".(P201/01:37:04) Mark was most excited about studying the Napoleonic historical period at university, he said "…*I knew that there was a Napoleonic major I could do so I was like so that's always been my favourite period of history. … also … academically in general*".(P201/01:30:47)

Ac-CSS (Evidence of good support practice)

He accessed Ac-CSS available to him at university namely '***autism specific support***' and had '***reasonable adjustments***' in place for exams ('***smaller room***', '***extra time***' and a '***laptop***').

> "*I knew I could have support. I didn't know to what extent… I think I've talked with* 'autism practitioner' *towards the beginning of first year … I got … a smaller room, 25% extra time and a laptop*".(P201/01:41:11)

However, he was not aware that he was entitled to Disabled Student Allowance (DSA) until his first term at university. He went on to explain how, from his second term, his DSA funded his additional Ac-CSS in the form of a '***specialist study skills tutor***' and ES-CSS in the form of a '***specialist autism mentor***'.

> "*DSA England* (funded) *… study skills … autism mentor… from the beginning of the second term of the first year. That's when I started to really have it*".(P201/01:41:11) He continued, saying that "*the second term … was definitely easier from that perspective*".(P201/01:52:43)

He specifically highlighted the Ac-CSS of his '***specialist study skills tutor***'.

> "… 'specialist tutor'*…she's been really, really helpful because basically she's helping with my writing style … I tend to be quite ambiguous in my speech probably because of the fast-flowing nature of it … then you sound very, very wishy-washy which isn't very helpful when you're trying to state something as if you know for a fact. And so* 'specialist tutor'*…definitely helping me with that kind of thing, with my writing style …. organisation as well… now I've got a system of timetables and everything so I can make sure I stay on track*".(P201/01:43:25)

4.4.6.3 Emotional-social concurrent stressors (ES-CS)

Mark expressed that he was slightly '**apprehensive disclosing (his) autism diagnosis**' but once he discussed this with the well-being team and realised having autism wasn't a 'big problem' he appeared reassured.

> "*...I had a little bit of apprehension about that but as soon as I started really talking to the people at Wellbeing, it was kind of really just kind of - because there was very much this nature within the Wellbeing Services of like this nonchalant because you people deal with it all the time and was like, "What's the problem?" …*".(P201/01:48:31)

Mark explained that he didn't really have social challenges during this CTT. The only challenge he shared was '**difficulties going to nightclubs because he was then unable to talk to his peers**'.

> "*Socially I didn't really find they were many issues for me simply because I was the one that was always willing to talk so I never really had an issue just talking with anyone. Obviously going to night clubs, the only issue is that you can't really tend to make … but certainly … in uni. … in class… anything like that, I had no problem. That was definitely never an issue and then obviously going to Eureka as well*".(P201/01:38:50)

Living in student accommodation Mark shared that he experienced CS as a result of '**not knowing the protocol around others who are being passionate and loving towards each other**'.

> "*Suddenly I'm in a situation where two people who are very, very passionate and loving towards each other are living next to me. What's protocol here? I have no guidelines in this situation. I think that's another issue with autism in general I think at least from my perspective is you often like instructions, 'Follow these guidelines, you'll be fine'. The problem is obviously life doesn't give you any guidelines*".(P201/01:36:17)

He hesitantly shared that he experienced CS at '**being surrounded by emotionally expressive people**' when he first started university. He stated that this helped him to get used to emotional expressions and to be more comfortable and confident with his own 'emotional situation'.

> "*Dealing with the fact that people were unbelievably emotionally expressive. I was suddenly after 18 years … suddenly I'm in a scenario where I'm living with a whole load of people that are now emotionally expressive. I now have loads of people that are now emotionally expressive and really comfortable in and of themselves being emotionally expressive and then I assume expecting me to be the same and that was like, "Oh, okay". … I guess I just kind of got more used to it. You get exposed to this kind of thing- I think it's just the fact that living with it 24/7 for a long enough period of time you do get used to emotional expressions… You become more familiar with it but also become more comfortable in and of yourself with your own emotional situation. It's the case of because someone's opened up themselves to you, you then feel more confident opening up to them to a certain degree at least…*".(P201/01:32:29)

By his final year he proudly shared that he, "…*definitely*",(P201/01:34:38) had become more emotionally expressive, that he now had "*the freedom to be able to do it* (emotionally express) *myself properly*".(P201/01:58:30) When Mark was asked what his greatest achievement had been emotionally during this CTT he proudly stated that it was changing from "…*emotional callousness to emotional expressive… going from internalising any sort of emotional feelings, et cetera, et cetera, to being able to express the feelings a lot more. I guess it's all self-confidence as well…*".(P201/02:05:28)

ES-CSS (Evidence of good support practice)

As outlined earlier, Mark got support for his ES-CS from the '***autism practitioner***' (well-being) and the '***Eureka peers***' (autism social group), "*...going to Wellbeing* (to see the autism practitioner) *on a pretty regular basis, going to Eureka, that kind of thing*".(P201/01:52:43) He mentioned that he spoke to his peers in '***Eureka***' about being autistic but didn't feel that he needed to disclose his autism to anyone else.

> "*...I feel like I could have but didn't want to* (talk about having autism) *...apart from those at Eureka. Because I was always speaking to people at Eureka about it, I was like, "Why do I need to talk to anyone else about it?" ...*".(P201/01:56:40)

He stated that he found his '***specialist autism mentor***' ES-CSS, "…*so helpful…mostly the fact that you are then able to talk to someone…it's one-on-one and you can talk about any kind of thing*".(P201/01:42:53) ES-CSS continued to be provided by '***Mum***'. Ac-CS was also provided by his DSA '***specialist study skills tutor***'.

4.4.7 Procedural step 3

The categorical-form analysis (CFA) of Mark's data enabled me (the researcher) to gain in-depth insight into his linguistic dialogue, namely his tones of voice and non-verbal communication. This was performed by using Mark's fabula notes and tagging frequency of nonverbal (sjuzet) occurrences within his narrative statements, using reflective diary entries. CFA data was categorised into fourteen varied tones, and nonverbals, and frequencies were calculated. CFA data relating to Mark's state of health, positive and negative tones, and non-verbals (n=9), were then used to illustrate tonal frequencies within his narrative. Table 4.1 (c) details fabula notes and tagged positive and/or negative nonverbal calculation for each CTT, which will be discussed in more detail in next sections (appendix 4.1 (a) details a breakdown of these calculations).

Table 4.1 (c): The positive and negative linguistic tones and nonverbals used by Mark during his interviews that were identified using the sjuzet data applied to statements made within the context of themes and subthemes.

		Percentage category occurrence of positive and negative linguistic tones/nonverbals in each CTT			
Tone or non-verbal used (frequency)	**Category (frequency)**	**Primary**	**Secondary**	**Sixth form**	**University**
relaxed (45) happy (18) excited (5) smiling (2) upbeat (2) laughing (1)	**Positive** (58*)	14%	31%	10%	>positive 45%
withdrawing (15) despondent (7) worried (1)	**Negative** (22**)	41% (29% of the total withdrawing tone used in this CTT) (>71% of the total despondent tone used in this CTT) (worried 0)	41% (>50% of the total withdrawing tone used in this CTT) (14% of the total despondent tone used in this CTT) (>100% of the total worried tone used in this CTT)	9% (7% of the total withdrawing tone used in this CTT) (14% of the total despondent tone used in this CTT)	9% (14% of the total withdrawing tone used in this CTT) (despondent 0)

*Positive (15 tones did not relate specifically to a CTT and have been excluded) (Total positive tones n=6)

**Negative (1 withdrawing tone did not relate specifically to a CTT and has been excluded) (Total negative tones n=3)

NB: Not included in this table were factual tones (n=1) and 'other' (including serious) (n=4) (Total tones n=5)

>Indicates the greatest frequency of tone type occurrence amongst all the CTTs

4.4.8 Procedural step 4

Holistic-form analysis (HFA) combined HCA, CCA, CFA results, using the HFA scoring matrix (chapter 3, section 3.6.6.3, table 3.3), to produce an HFA numerical score that could then be attributed to a CTT (calculation shown in appendix 4.1 (b)). This score was then compared with another CTT to gauge Mark's narrative progression or regression. HFA score also enabled consideration of the structure of Mark's narrative, how he positioned himself within it, his typology, cohesion within his narrative and any turning points. The 'overall' core of Mark's transitioning story showed a regressive, then progressive narrative (figure 4.1 (a)). The limitations of using a scoring matrix are discussed in section 6.7.

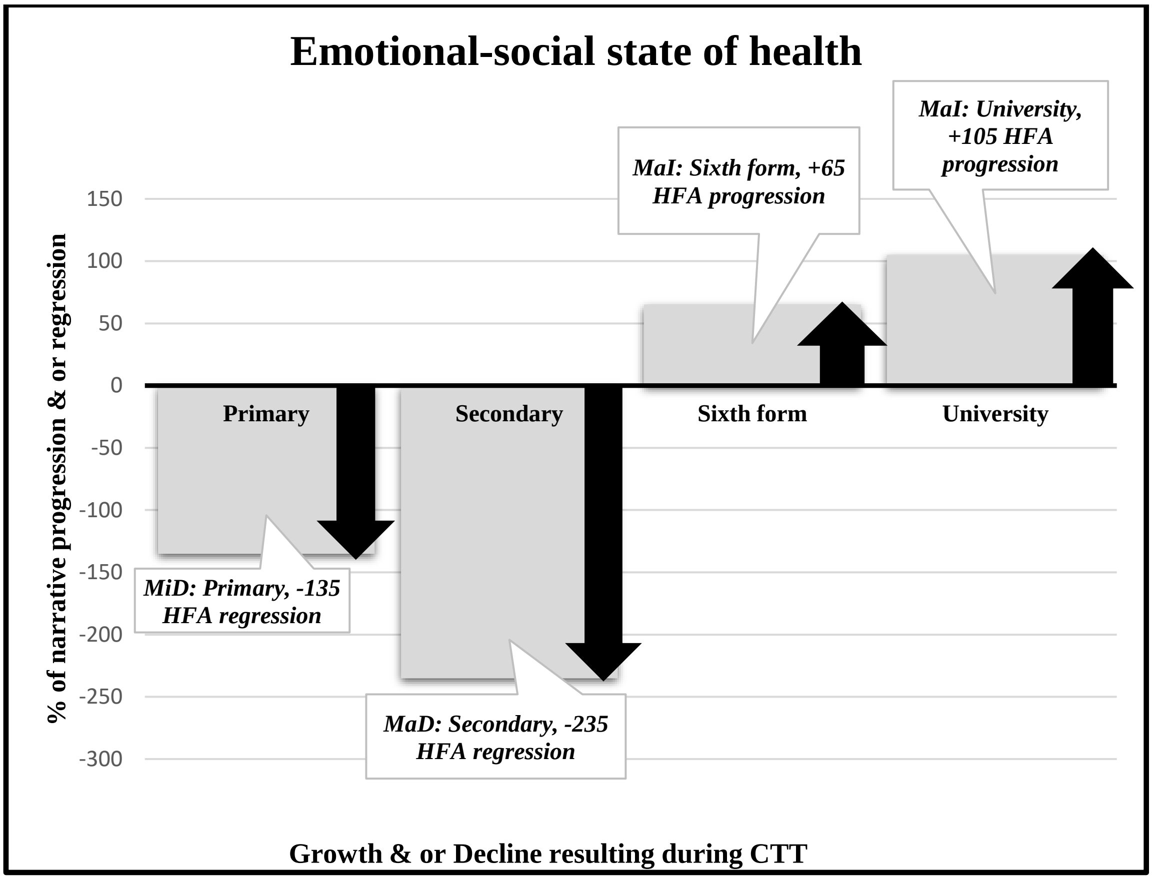


Figure 4.1 (a): Holistic-form: Narrative regression and progression of Mark's Core Story, CTT, TST, in relation to state of health. MiD = Minor deterioration in state of health / MaD = Major deterioration in state of health / MiI = Minor improvement in state of health / MaI = Major improvement in state of health

The primary CTT demonstrated -135 HFA regressive narrative decline (figure 4.1 (a) column 1). This CTT had the greatest occurrence of CFA minor negative-despondent tones used (table 4.1 (c)) when discussing ES-CS experiences compared with other CTT. This tone was classified as a minor negative CFA tone and is thus suggestive of a negative experience. Mark's data indicated that he experienced a minor deterioration in state of health (MiD) during this CTT due to an increase in some ES-CS, '**social anxiety**', '**inability to express his emotions due to upbringing**' and '**being stuck in a negative friendship he wanted to end**'.

The secondary CTT demonstrated -235 HFA regressive narrative decline (figure 4.1 (a) column 2). This CTT had the greatest occurrence of CFA minor negative-withdrawing tones when discussing Ac-CS, ES-CS, EST-CS experiences, and minor negative-worried tones discussing ES-CS experiences, compared with other CTT (table 4.1 (c)). Thus, Mark's data indicated that he experienced a major deterioration in state of health (MaD) during this CTT. This secondary CTT appeared to be a major negative turning point for Mark, due to ongoing CS and an increase in some ES-CS, '**social anxiety**', '**being bullied due to being naïve**', '**social confusion**', '**stigma about being autistic and worrying about his peer**'**s reaction to this**'.

The sixth form CTT demonstrated +65 HFA progressive narrative growth (figure 4.1 (a) column 3). Mark's data indicated that he experienced a major improvement in state of health (MaI) during this CTT, due to no mention of ES-CS, implying that he overcame previous CS or that these were considerably reduced. He did, however, continue to express concerns relating to, '**stigma about being autistic and worrying about his peer**'**s reaction to this**' CS. This CTT, appeared to be a major positive turning point for Mark, with a major improvement in ES overall. This was likely to be due to the Ac-CSS and ES-CSS that accompanied his autism diagnosis (aged 17 years) and his ability to gain a greater self-understanding.

The university CTT demonstrated +105 HFA progressive narrative growth (figure 4.1 (a) column 4). This CTT had the greatest occurrence of CFA major positive tones discussing Ac-CS, ES-CS, EST-CS, and CSS experiences, compared with other CTT (table 4.1 (c)). Thus, Mark's data indicated that he experienced a major improvement in state of health (MaI) during this CTT, evidenced by major improvement in ES overall, based on ongoing improvement in his ES health, implying that he overcame previous CS or that these were considerably reduced.

4.4.8.1 Mark’s Typology

HFA revealed Mark’s typology changed drastically throughout his narrative. Initially, during his primary, secondary, sixth form, CTTs, he presented himself as having an ‘emotionally callous’ typology, unable to express his emotions to others and to himself. When Mark arrived at university, he stated that he was surrounded by emotionally expressive peers, he described transforming into an ‘emotionally expressive’ typology. He expressed his belief that this resulted from a growth in his ability to express and understand emotions. Typology will be discussed in detail in step 6, section 4.4.10.

Table 4.1 (d): Calculation of Mark's Holistic-form analysis score combining HCA, CCA, CFA narrative data. HCA = holistic-content analysis, CCA = categorical-content analysis, CFA = categorical-form analysis, HFA = holistic-form analysis, CTT = core transitioning theme, CS = concurrent stressor, Ac = academic, ES = emotional-social, MiD = minor deterioration to state of health, MaD = major deterioration to state of health, MiI = minor improvement to state of health, MaI = major improvement to state of health

	Holistic-form analysis frequency and score							
	Primary		**Secondary**		**Sixth form**		**University**	
(i) Previously identified CS	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**
Major Ac-CS (impacting state of health) $^{(f\ \mathrm{x}\ -5)}$	f = 1	n = - 5	f = 1	n = - 5	f = 1	n = - 5	f = 1	n = - 5
Minor ES-CS $^{(f\ \mathrm{x}\ -5)}$	f = 7	n = - 35	f = 12	n = - 60	f=2	n = - 10	f = 6	n = - 30
Major ES-CS $^{(f\ \mathrm{x}\ -10)}$	f = 2	n = - 20	f = 2	n = - 20	f = 2	n = - 20	f = 1	n = - 10
(ii) CFA linguistic (nonverbal) results	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**
Minor negative CFA $^{(f\ \mathrm{x}\ -25)}$	f = 1	n = - 25	f = 2	n = - 50	-	-	-	-
Major negative CFA $^{(f\ \mathrm{x}\ -50)}$	-	-	-	-	-	-	-	-
Minor positive CFA $^{(f\ \mathrm{x}\ +25)}$	-	-	-	-	-	-	-	-
Major positive CFA $^{(f\ \mathrm{x}\ +50)}$	-	-	-	-	-	-	f = 1	n = +50
(iii) State of health	**Category (HFA total score)**		**Category (HFA total score)**		**Category (HFA total score)**		**Category (HFA total score)**	
MiD $^{(f\ \mathrm{x}\ -50)}$	n = - 50		-		-		-	
MaD $^{(f\ \mathrm{x}\ -100)}$	-		n = -100		-		-	
MiI $^{(f\ \mathrm{x}\ +50)}$	-		-		-		-	
MaI $^{(f\ \mathrm{x}\ +100)}$	-		-		n = + 100		n = +100	
	Total primary HFA score		**Total secondary HFA score**		**Total sixth form HFA score**		**Total university HFA score**	
	n = - 135 (regressive narrative decline)		n = - 235 (regressive narrative decline)		n = + 65 (progressive narrative growth)		n = + 105 (progressive narrative growth)	

4.4.9 Procedural step 5

To be able to illustrate to the reader Mark’s ability to adapt to a CTT, I encompassed Mark’s HCA, CCA, CFA, HFA data into the ‘educational transitioning model’, which visually detailed; (1) any CS that impacted his state of health, (2) ‘self’ characteristics, (3) concurrent stressor support (CSS), (4) previous CTT state of health compared with current state of health. The educational transitioning models (figures 4.1 (b)-(e)) summarise Mark’s lived experiences and educational journey in relation to his state of health.

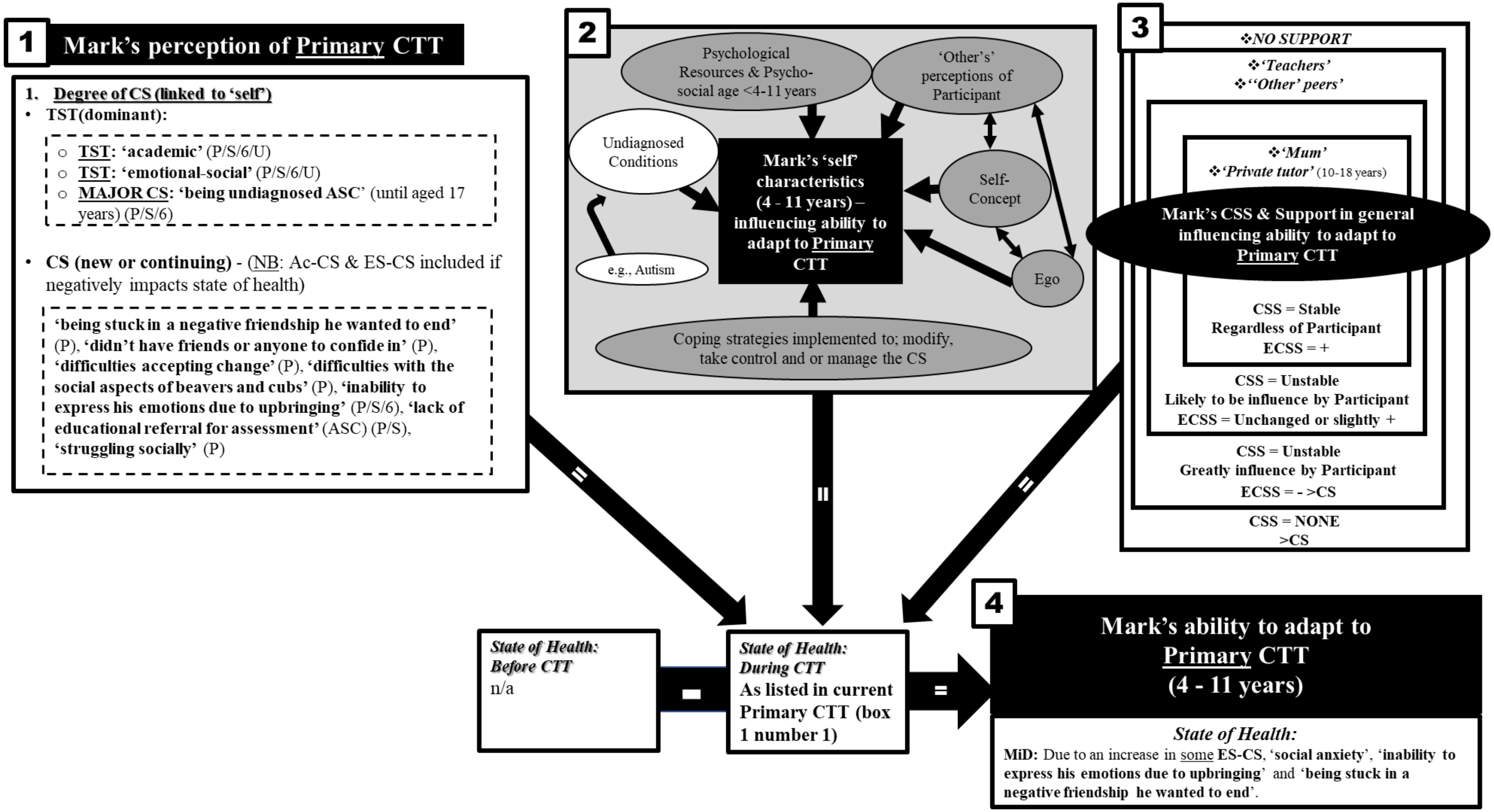


Figure 4.1 (b): Educational transitioning model representing Mark's ability to adapt to the primary CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268]

For abbreviations see chapter three, table 3.4.

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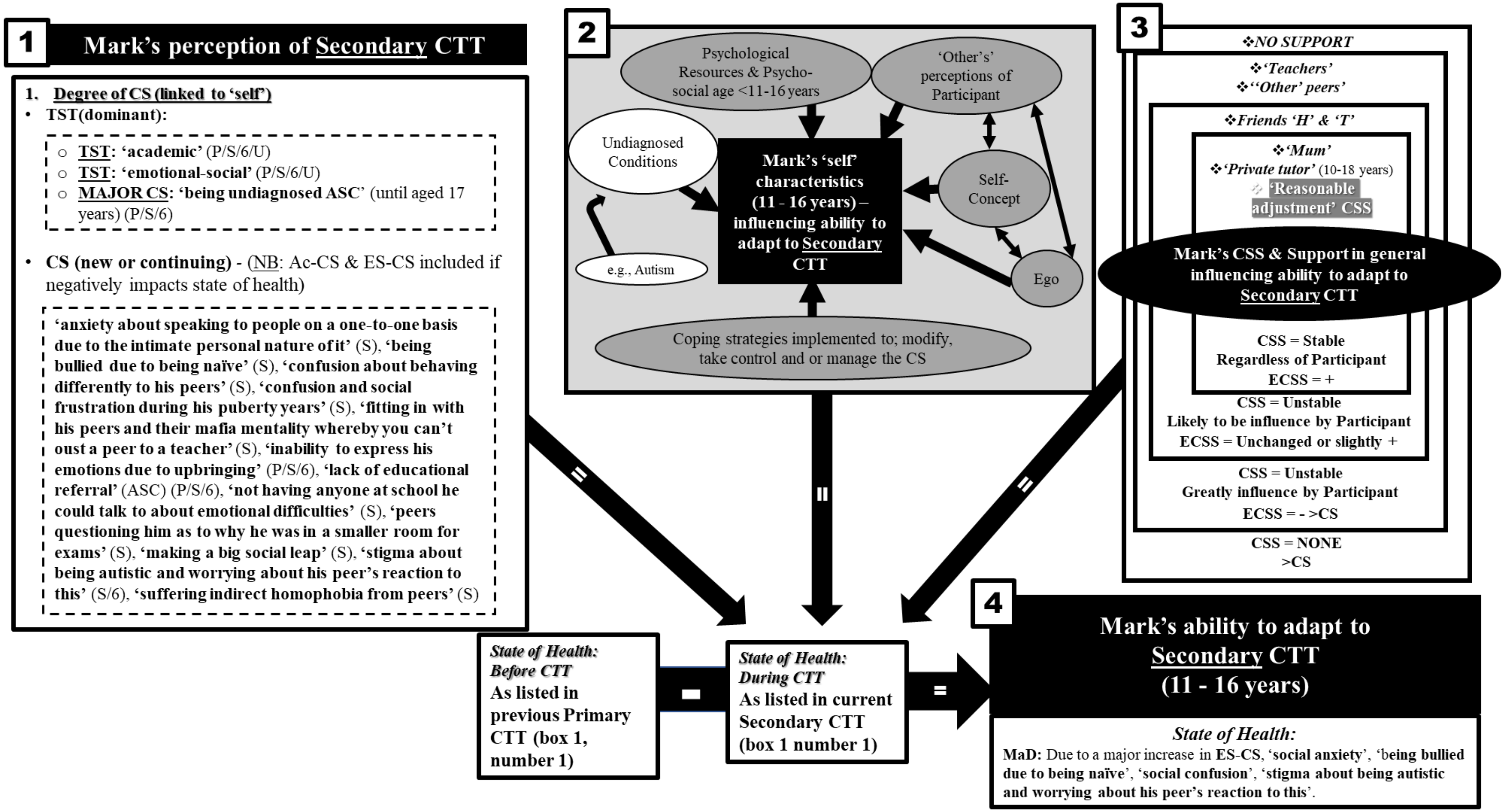


1. **Degree of CS (linked to 'self')**

- **TST(dominant):**
  - **TST: 'academic'** (P/S/6/U)
  - **TST: 'emotional-social'** (P/S/6/U)
  - **MAJOR CS: 'being undiagnosed ASC'** (until aged 17 years) (P/S/6)
- **CS (new or continuing)** - (NB: Ac-CS & ES-CS included if negatively impacts state of health)

'anxiety about speaking to people on a one-to-one basis due to the intimate personal nature of it' (S), **'being bullied due to being naïve'** (S), **'confusion about behaving differently to his peers'** (S), **'confusion and social frustration during his puberty years'** (S), **'fitting in with his peers and their mafia mentality whereby you can't oust a peer to a teacher'** (S), **'inability to express his emotions due to upbringing'** (P/S/6), **'lack of educational referral'** (ASC) (P/S/6), **'not having anyone at school he could talk to about emotional difficulties'** (S), **'peers questioning him as to why he was in a smaller room for exams'** (S), **'making a big social leap'** (S), **'stigma about being autistic and worrying about his peer's reaction to this'** (S/6), **'suffering indirect homophobia from peers'** (S)

State of Health:

MaD: Due to a major increase in **ES-CS**, '**social anxiety**', '**being bullied due to being naïve**', '**social confusion**', '**stigma about being autistic and worrying about his peer's reaction to this**'.

Figure 4.1 (c): Educational transitioning model representing Mark's ability to adapt to the secondary CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268]

For abbreviations see chapter three, table 3.4.

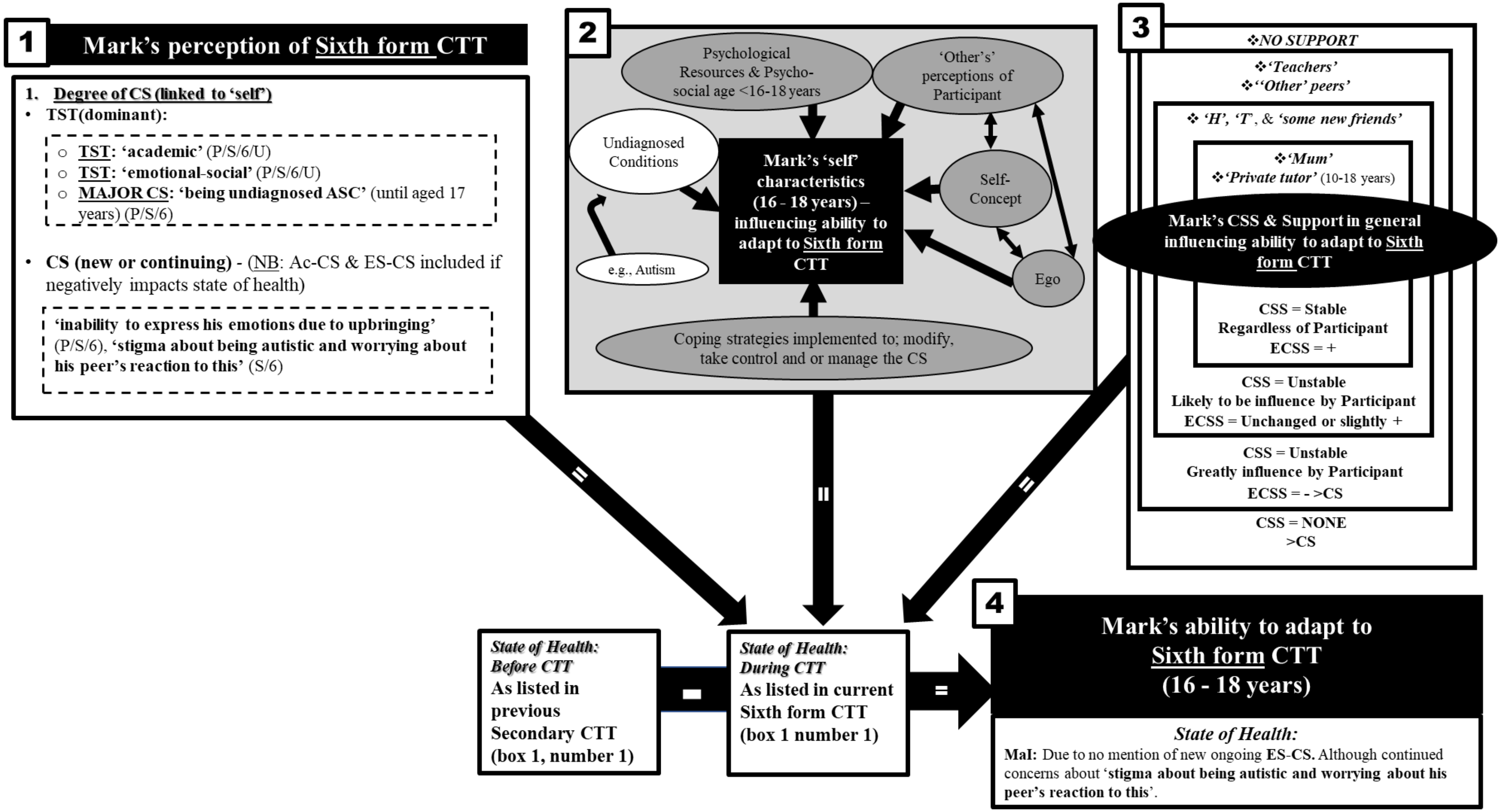


Figure 4.1 (d): Educational transitioning model representing Mark's ability to adapt to the sixth form CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

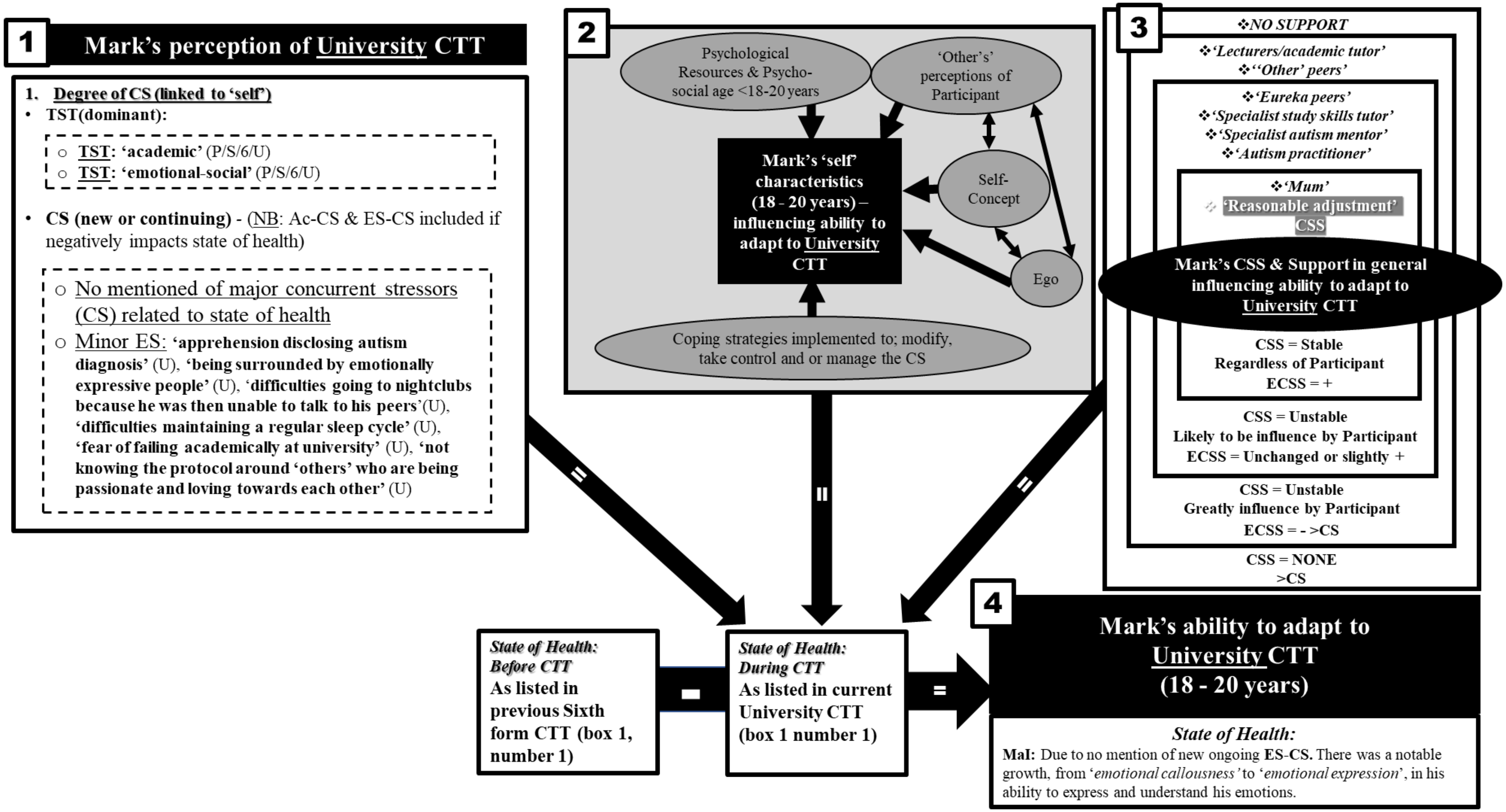


Figure 4.1 (e): Educational transitioning model representing Mark's ability to adapt to the university CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268]

For abbreviations see chapter three, table 3.4.

4.4.10 Procedural step 6

Critical narrative analysis (CNA) considered the functionality of Mark's story, how he was positioned within it, by considering the fabular and sjuzet properties reflecting his; thoughts, feelings, emotions, actions, interactions, achievements, challenges, and the social structure in which his story takes place. CNA identified a critical positioning theme; namely that Mark initially had an 'emotionally callous' typology during primary, secondary, sixth form CTT, which transformed into an 'emotionally expressive' typology during the university CTT.

4.4.10.1 Mark's positive transformation from an 'emotionally callous' typology to an 'emotionally expressive' typology

Mark's described himself throughout his primary and secondary CTT as 'emotionally closed off' and cited that this was due to, "*being raised in a household where emotional expression isn't talked about let alone accepted*".(P201/00:25:59) During his primary CTT he recalled how he would respond to emotional questioning by using a rote response such as "*yeah fine*",(P201/00:25:59) rather than truly thinking about how he was feeling emotionally and then sharing these feelings. In the early part of his secondary CTT, aged 13 years, Mark started private tuition, this was when he became aware that others outside of his family unit were emotionally expressive, which he appeared shocked to discover.

> "*…such a shock for the first few years when I met* 'private tutor' *because she was emotionally expressive. It took me years to get around that because suddenly I've spent 13 years inside a household where no one's emotionally expressive*".(P201/00:26:33)

Mark demonstrated good support practice, with his private tutor encouraging him to question his learnt 'emotionally callous' typology. He shared how emotionally expressive individuals confused him and how he logically hypothesized his response to them by consciously rationalising how he should act and how he should respond. The university CTT, when he was surrounded by emotionally expressive individuals, resulted in Mark's typology transforming from being, 'emotionally callous' to 'emotionally expressive'. By this stage Mark's self-advocacy skills improved greatly, sharing how he had gained the skills to express his emotions and feelings, rather than internalising them, and that this was connected with a growth in his self-confidence overall.

4.4.11 Summary of Mark’s ability to adapt to each core transitioning theme

HCA: CTT; primary, secondary, sixth form, university.
CCA: TST; academic (Ac), emotional-social (ES).
CFA: Greatest occurrence of minor negative-despondent tones during primary CTT. Greatest occurrence of minor negative-withdrawing and minor negative-worried tones during secondary CTT. Greatest occurrence of major positive tones during university CTT.
HFA: Indicated a regressive-progressive narrative.
HFA & CNA: HFA linguistical analysis and CNA revealed an ‘emotionally callous’ typology evolving into ‘emotionally expressive’ typology in university CTT.

HCA, **CCA**, **CFA**, **HFA**, **combined (table 4.1 (d)):**
<u>Primary</u> CTT, evidences a regressive narrative. This CTT had the greatest occurrence of CFA minor negative-despondent tones compared with other CTT. Evidence of good support practice took the form of: Stable CSS (regardless of behaviour) was provided by ‘***Mum***’ and his ‘***private tutor***’ (in his final year). Data indicated a minor deterioration in state of health evidenced by an increase in some ES-CS, ‘**social anxiety**’, ‘**inability to express his emotions due to upbringing**’ and ‘**being stuck in a negative friendship he wanted to end**’.
<u>Secondary</u> CTT, evidences a regressive narrative. This CTT had the greatest overall HFA narrative regression, compared with other CTT. This CTT had the greatest occurrence of CFA minor negative-withdrawing and worried dialogues, suggestive of negative experiences, compared with other CTT. Evidence of good support practice took the form of: Stable CSS continued to be provided by ‘***Mum***’ and his ‘***private tutor***’, unstable positive CSS was provided by friends ‘***H***’ and ‘***T***’. ‘***Reasonable adjustments***’ CSS were put in place (without autism diagnosis). Data indicated a major deterioration in state of health evidenced by ongoing CS and an increase in some ES-CS, ‘**social anxiety**’, ‘**being bullied due to being naïve**’, ‘**social confusion**’, ‘**stigma about being autistic and worrying about his peer**’**s reaction to this**’.

Sixth form CTT, evidences a progressive narrative. Evidence of good support practice took the form of: Stable CSS continued to be provided by '***Mum***' and his '***private tutor***', unstable positive CSS by '***H***', '***T***', and '***some new friends***'. It was not possible to put reasonable adjustments CSS in place due to being undiagnosed until final year which was too late for his exams. Data indicated a major improvement in state of health evidenced by no mention of ES-CS, implying that he overcame previous CS or that these were considerably reduced, as well as Ac-CSS and ES-CSS that accompanied his autism diagnosis (aged 17 years) and his ability to gain a greater self-understanding.

University CTT, evidences a progressive narrative. This CTT had the greatest occurrence of CFA major positive tones compared with other CTT. Evidence of good support practice took the form of: Stable CSS continued to be provided by '***Mum***'. Unstable positive CSS was provided by '***Eureka peers***', from a '***specialist study skills tutor***', '***specialist autism mentor***' and '***autism practitioner***'. There was '***reasonable adjustments***' CSS. Data indicated a major improvement in state of health evidenced by a major improvement in ES overall, based on ongoing improvement in his ES health, implying that he overcame previous CS or that these were considerably reduced.

4.5 Karen’s story

4.5.1 Background and setting

The initial participant interview with Karen took place in her current university in a private lounge area. At the time of the interview, Karen was in the final year of her part-time computer science MSc.

4.5.2 Procedural steps 1-2: Overview

The holistic-content analysis (HCA) of Karen’s data is reflected in table 4.2 (a), the core transitioning themes (CTT) that emerged from her educational journey narrative. Two overarching TSTs were identified, namely ‘**academic**’ (Ac) and ‘**emotional-social**’ (ES). The ‘**emotional-social**’ (ES) subtheme has been grouped to include CS related to this heading such as; bullying, discrimination, friendship, group interactions, mental health (e.g., anxiety, fears, phobias, self-harm, stress), social anxiety, stigma, and so on.

Table 4.2 (a): Holistic-content analysis overview: Karen’s core transitioning themes (CTT) and transitioning sub-themes (TST). Her age during each CTT is indicated within the brackets.

	Core transitioning themes (CTT)				
	Primary School (4-11 years)	**Secondary School (11-16 years)**	**Sixth form (16-18 years)**	**University (BSc) (18-21 years)**	**University (MSc) (23-25 years)**
Transitioning sub-themes (TST)	Academic (Ac) Emotional-Social (ES)				

The categorical-content analysis (CCA) of Karen’s data, enabled a more in-depth examination of each CTT to look for patterns. For each CTT, Karen’s narrative was examined for the appearance of the specific concurrent stressors (CS) experienced by her (table 4.2 (b)) with the sections that follow giving context and describing them in detail. In the primary, secondary, sixth form and university (BSc) CTTs their appearance appeared to be exacerbated by the overarching or major ES-CS ‘**being undiagnosed ASC**’ which was likely to have had impacts on both the ‘**academic** ‘ (Ac) CS and ‘**emotional-social**’ (ES) CS.

Table 4.2 (b): Categorical-content analysis overview: Karen’s transitioning sub-themes (TST) and concurrent stressors (CS). Table also shows the core transitioning themes (CTT) or timepoints where the CS occurred. P = primary, S = secondary, 6 = sixth form, UBSc = undergraduate university, UMSc = postgraduate university

Transitioning sub-themes (TST)	**Concurrent stressors (CS)**	**Time point(s)**				
		P	**S**	**6**	**UBSc**	**UMSc**
	Major CS: ‘being undiagnosed ASC’ (until aged 20 years) **(Un)**	**P**	**S**	**6**	**UBSc**	
‘academic’ (Ac)						
	‘adapting to a fact-based course					**UMSc**
	‘believing that she must get ‘A’ grades in her exams to be successful’		**S**			
	‘D grade in PE’		**S**			
	‘difficulties knowing how to start an assignment’				**UBSc**	
	‘difficulties organising, prioritising, planning, scheduling, and structuring her course work so that it wasn’t last minute’				**UBSc**	
	‘difficulties processing what lecturers said in the context of the lecture’				**UBSc**	
	‘keeping up with the background reading’				**UBSc**	
	‘speaking in seminar groups in front of her peers’				**UBSc**	
	‘stress due to the academic pressure of deadlines’				**UBSc**	
	‘that it was a big academic jump’					**UMSc**
‘emotional-social’ (ES)						
	‘difficulty socialising with peers’		**S**			
	‘falling out with her friend who she lived with during her second year resulting in her having to live separate from her friends in her third year’				**UBSc**	
	‘fear that she couldn’t finish her undergraduate degree’				**UBSc**	
	‘feeling left out by her peers’		**S**			
	‘feeling like she did not fit in with her peers’		**S**			
	‘feeling like she did not fit in with her peers and being social awkward’				**UBSc**	
	‘feeling that something was different about her but not knowing what’		**S**			
	‘finding it difficult to make friends with peers on her course’					**UMSc**
	‘in her third year not seeing her friends from before as much’				**UBSc**	
	‘meltdowns due to being frustrated by a challenging activity’		**S**			
	‘not knowing how to deal with stuff…’		**S**			
	‘not making new friends in her final year’				**UBSc**	
	‘that the university might think less of her due to her ASC diagnosis’					**UMSc**
	‘that the university might think she shouldn’t be in university due to her ASC diagnosis’					**UMSc**
	‘when she first started primary school, she found it difficult to make friends’	**P**				
‘emotional-social transitioning’ (EST)						
	‘fear about living independently’					**UMSc**
	‘fear about living with new people’					**UMSc**
	‘fear about moving away from home’				**UBSc**	
	‘fear about returning to academic studies’					**UMSc**
	‘fear about the long journey she had to make to sixth form’			**6**		
	‘fear of change’				**UBSc**	
	‘fear that she would not get along with her sixth form peers’			**6**		
	‘feeling homesick’				**UBSc**	
	‘greater CS starting her MSc compared with what she felt starting her BSc’					**UMSc**
	‘guilt about not getting used to university life as quickly as she thought she should’				**UBSc**	
	‘uncertainty about whether she wanted to go to university or not’				**UBSc**	
	‘whether she had sufficient independent living skills to live alone’				**UBSc**	
	‘worried that she wouldn’t be able to keep up with the course and do the exams’					**UMSc**

4.5.3 Procedural steps 1-2: Primary CTT

4.5.3.1 The major concurrent stressor 'being undiagnosed ASC' (Un-CS)

Karen stated that her parents became aware that she was neuro-diverse during this primary CTT when she was 10 years old. Although, she continued "*...when I was five* (primary school) ... *they had me tested, and it was borderline… dyspraxia*",(P202/0:01:26) but an official diagnosis was not given at this stage.

4.5.3.2 Academic concurrent stressors (Ac-CS)

Karen happily described that she got on well academically during this primary CTT. She said, "*academically it was good, yeah…*" and when asked if she needed or received any Ac-CSS, she continued by saying "*...I don't think so*".(P202/0:07:29)

4.5.3.3 Emotional-social concurrent stressors (ES-CS)

In a contemplative tone, Karen shared,"*... I don't think I was an anxious child*",(P202/0:08:46) during her primary CTT. However, hesitantly she expressed CS, '**when she first starting primary school**, **she found it difficult to make friends**' but after her peers attended a birthday party, arranged by her parents, she then "*... got on with people*".(P202/0:07:44) Smiling and using open positive communication Karen shared that she formed lifelong friendships during her primary CTT with two of her peers, sharing that, "*... me and* 'B', *and* 'S'*... we talk sometimes* (now)".(P202/0:08:20)

ES-CSS (Evidence of good support practice)

Karen's primary school '***teachers***', her peers '***B***' and '***S***', '***Mum***' and '***Dad***', provided ES-CSS.

4.5.4 Procedural steps 1-2: Secondary CTT

4.5.4.1 Emotional-social transitioning concurrent stressors (EST-CS)

Transitioning from the primary to secondary CTT appeared to be a positive experience for Karen, that she was "…*excited about it…*",(P202/0:09:43) although she did express that she was "…*nervous as well*".(P202/0:09:43)

<u>EST-CSS</u> (Evidence of good support practice)
Karen's primary school provided her with EST-CSS in the form of '***a book that explained what secondary school would be like***', something that she stated she, "…*must've read that, like, ten times*".(P202/0:09:43) She also recalled how the secondary school provided EST-CSS, '***sending their*** (secondary) ***teachers to her primary school for an induction day***'.

> "*We had one day, in the summer, when the teachers came to the school, ... they just took us all to the one room for the day and talked to us*".(P202/0:09:43)

4.5.4.2 Academic concurrent stressors (Ac-CS)

Karen stated that she was, "*good academically*".(P202/0:11:25) Although, later in the interview she referred back to her secondary CTT describing that she experienced Ac-CS during this CTT due to '**believing that she must get 'A' grades in her exams to be successful**', stating, "*I got a B in Science… thinking that was a bad thing... 'cause it in* (secondary) *school it would have been*".(P202/0:21:14) During this secondary CTT her parents were approached by a teacher due to her getting a 'D' grade for physical education (PE). She shared that her parents discussed with this teacher and reasoned that she had undiagnosed dyspraxia which they believed resulted in her difficulties doing PE and her experiencing '**D grade in PE**' CS. Karen stated that her parents were definite in their opinion to not pursue a diagnosis for her, that at this stage their opinion was that "*...she's fine. We don't want labels or anything*".(P202/0:01:34) Karen also mentioned that her teacher thought that she, "… *might have some kind of hearing problem as well*".(P202/0:25:18)

4.5.4.3 Emotional-social concurrent stressors (ES-CS)

Karen stated that the greatest challenge that she faced during her educational journey was '**social**' CS, and that this was particularly challenging during her secondary CTT. She went on to reason that she felt this was because she lacked, "*…social skills, I reckon. In secondary school, mainly*". (P202/01:09:24) She referred to her secondary CTT as a period when, "*…it started happening all kind of meltdowns... if I got frustrated with something… I'd get really annoyed… then maybe I'd cry*".(P202/0:15:22) This resulted in her having frequent CS '**meltdowns due to being frustrated by a challenging activity**'. When asked if these meltdowns occurred in school Karen responded that they didn't, "*…no, I don't think so*".(P202/0:16:02) Emotionally, Karen reasoned that she experienced ES-CS because of '**not knowing how to deal with stuff**…', during this CTT. Hesitantly she continued to share that she experienced CS due to '**feeling left out by her peers** ' and '**feeling that something was different about her but not knowing what**'.

> "*I guess I just didn't really know how to deal with stuff, and... I guess I felt kind of left out from... from other people? Like I might have something different, but I didn't know why, or anything*".(P202/0:16:28)
>
> "*... I don't know why… I guess, maybe I thought I could just ignore it*".(P202/0:17:24)

Timidly, twisting her hands together, Karen stated that she didn't get on well socially during her secondary CTT. Expressing that she didn't talk to many people, due to CS, '**difficulty socialising with peers**' and '**feeling like she did not fit in with her peers**'.

> "... (socially) *not very well. I didn't really talk to people much... ...and, you know, it's secondary school, so... I think more like it's easier when you're a little kid to get on with people… and then I guess, growing up into secondary school and I just didn't really fit in as much anymore*".(P202/0:12:46)

<u>ES-CSS</u> (Evidence of good support practice)

Rather than seeking ES-CSS from others at this time, Karen attempted to ignore her ES-CS, although ‘***teachers***’ did appear to provide some ES-CSS. Karen stated that she did have a ‘***couple of peers***’ that she spent time with during this secondary CTT. She met these peers through an extra curricula book club that the school ran. She described spending time with them in their homes and going to the cinema with them.

> “*A couple, yeah… two people, yeah… We’d hang out a lot at lunch time, and things... ...I met them from… book club… we’d go to the cinema, and I’d go to her house sometimes*”.(P202/00:13:24)

ES-CSS continued to be provided by ‘***Mum***’ and ‘***Dad***’.

4.5.5 Procedural steps 1-2: Sixth form CTT

4.5.5.1 Emotional-social transitioning concurrent stressors (EST-CS)

Before starting she experienced the EST-CS of, '**fear that she would not get along with her sixth form peers**' and '**fear about the long journey she had to make to sixth form**'.

> "*If it was going to be the same as… secondary school... and I still don't get along with people, and... still being, like, outside. And... because it was further away ... I had to take the train in*".(P202/0:18:39)

However, on a positive note she appeared to view the sixth form as an opportunity "*... to do the different subjects that they didn't have in the school…. and...and meeting new people, and like, fresh start, kind of thing*".(P202/0:18:39) The first day of sixth form Karen factual explained that she thought it was, "s*cary because it was big... bigger than school... it was like, wow, so many people*",(P202/0:21:01) and that she enjoyed being, "*…more independent*".(P202/0:22:08)

EST-CSS (Evidence of good support practice)
Karen recalled that the sixth form college, '***teachers***' provided her with EST-CSS prior to starting in the form of an '***open day***'. During this day she recalled having lessons and being given the opportunity to explore the campus. She described the experience as, "*good to do*".(P202/0:19:53)

'***Mum***' and '***Dad***' provided Karen with EST-CSS, taking her to the college interview, helping her to work out how she was going to travel to and from college.

> "*Yeah. Yeah, they* (mum and dad) *did* (help)*… me and mum went around the day after the interview into* 'the college'*... and they* (mum and dad) *helped me work out, like, how to get a train, a season pass thing and what...what trains I could get to there... so, it was useful*".(P202/0:20:27)

4.5.5.2 Academic concurrent stressors (Ac-CS)

Karen did not express any Ac-CS during her sixth form CTT when she studied, "… *Psychology, and French, and English*".(P202/0:26:50) Laughing she stated that sixth form felt like "*freedom*" compared to her previous school CTT, and "*...college... Oh, I was so happy… I didn't like school… I was like, yes, freedom!*"(P202/0:18:17)

4.5.5.3 Emotional-social concurrent stressors (ES-CS)

Factually, in a friendly tone, Karen stated that sixth form was "*good… I can't think of anything… major* (emotional-social) *that was going on*".(P202/0:24:05) She described how '**social**' CS reduced greatly. She said this was due to "*some excellent people from my English class...* 'C' *...hanging out with all my friends*".(P202/0:22:34) Fitting in to sixth form college didn't appear to be a problem for Karen. Smiling she explained that she "*fit in quickly, it was good*". Although she did continue by sharing that it was "… *a lot to get used to at first*".(P202/0:21:14) Gesturing and tapping her hands together, she elaborated on a sixth form college rivalry that took place between "*people in upstairs café and downstairs…*", that '*the weirdoes*' went to the upstairs café, and how she'd found 'her place' with them as they were the people most like her.

> "*... I was upstairs... 'cause...yeah, that...I mean, that's my place, the weirdoes… ...it was definitely good for me to meet all different kinds of people*".(P202/0:22:34)

Karen appeared surprised by her peers attitudes to exam grades, how her peers thought her B grade in science was 'a good mark'. Hearing her new peers say this appeared to ease Karen's CS previously experienced during secondary school when '**believing that she must get 'A' grades in her exams to be successful**'. Overall, Karen factually shared that she felt less Ac-CS and ES-CS during sixth form college, due to reduced pressure to be 'the best all the time'.

> "*I thought it* (sixth form) *was good, it was, like, less pressure... it was easier for me… you didn't have to be the absolute...absolute best all the time*".(P202/0:21:41)

<u>ES-CSS</u> (Evidence of good support practice)

Karen received ES-CSS from ‘***teachers***’ and her ‘***form tutor***’ however she did not think that her sixth form teachers were aware of her undiagnosed autism and did not receive autism specific CSS, “…*I don*’*t think so*”.(P202/0:25:05) She did receive ES-CSS from ‘***close friends***’, especially ‘***C***’, as well as continuation of ES-CSS from ‘***Mum***’ and ‘***Dad***’.

4.5.6 Procedural steps 1-2: University (BSc) CTT

4.5.6.1 Emotional-social transitioning concurrent stressors (EST-CS)

Prior to starting university Karen described hesitantly that she experienced EST-CS due to '**fear of change**', that she was, "*…scared, mostly… about the change in general*".(P202/0:27:26) She explained her EST-CS, in a serious tone, '**uncertainty about whether she wanted to go to university or not**' and that this resulted in her avoiding making any decisions.

> "*I wasn't … really sure if I wanted to go to uni or not. I kind of tried to avoid the whole thing for a while*".(P202/0:27:20)

After what appeared to be a lot of contemplating she did decide to go to university due to Mum and Dad sitting her down and, "*basically, like (said)… you have to decide what to do*".(P202/0:27:20) She continued by describing the things that scared her, prior to starting university, timidly stated that she experienced '**fear about moving away from home**', "*… moving away, I guess*".(P202/0:28:03) Although, in contradiction to this, Karen smiled and said that she, "*... wanted to move away … I guess I just thought it would be, like, good for me, to be more independent*".(P202/0:28:12) However, thinking about being independent triggered, '**whether she had sufficient independent living skills to live alone**' CS. Karen also shared she feared she would continue to experience, '**feeling like she did not fit in with her peers**', that she was, "*…worried about fitting in... like socially*".(P202/0:29:45)

Once a decision had been made to apply to her chosen university, Karen, gesturing and tapping her hands in a positive manner, stated that she was most excited about this, especially doing a creative writing degree. She appeared especially excited about the fact that her creative writing lecturer, had written a book, that she had, "*… read… that was really exciting… and then I was like, wow, real writers go there*".(P202/0:28:28) Karen was contemplative sharing how she prepared for university and living independently for the first time. How she remembered consciously acknowledging that, "*…I had to...start doing more things on my own*".(P202/0:40:56)

Arriving at her university Karen stated that she was scared, but that this experience ended up being a positive one. Factually she shared how it was, "*… good as well… and, like, first talking to my other flat mates... there was eight of us there... and we just got on, like, right away... and... yeah, it was really good*".(P202/0:31:26) She expressed CS, '**feeling homesick**' in the early stages of university life, and '**guilt about not getting used to university life as quickly as she thought she should**'.

> "*I felt kind homesick at the start... and then I kind of felt like I shouldn't be feeling like that, you know... kind of guilty... like I should be more...I don't know, I just...should just get used to something more quickly ... and kind of expected that I would*".(P202/0:37:14)

<u>EST-CSS</u> (Evidence of good support practice)

Karen's '***sixth form tutor***' provided her with EST-CSS, to '***prepare for university***', during sixth form registration periods.

> "*So, I had help from my tutor... we had a tutor who did our registration, and we'd see them every week, and... talk to them, like, if you had problems, kind of thing... and you could sit down with him and go through your UCAS application, and... we did, like, some practice, interviews, and things*".(P202/0:30:03)

University EST-CSS was provided by 'the chosen' university which she stated she went to visit during '***an open day***'. During this open day she positively shared that she '***attended a*** '***pretend***' ***lecture***', '***looked at the student accommodation and the campus in general***'.

> "*So, I went to their open day, and then after the open day they had like… a day... as well... I went to that too… I did like a lecture; you could go and see what that would be like... and then they showed you, like, around the halls where you might be living... and...and then I think we just went around the campus*".(P202/0:30:37)

CSS transitioning into university was provided by her '***parents***', "*… mum showed me, like, and got me doing more cooking, clean the house... and...and then dad went through, like, budgeting and things*".(P202/0:40:56)

4.5.6.2 The major concurrent stressor 'being undiagnosed ASC' (Un-CS)

During university, Karen continued to experience overarching CS '**being undiagnosed ASC**', until she was in her final year of her undergraduate degree. This late diagnosis resulted in her not receiving any reasonable adjustments, such as extra time, in time for the remainder of her course.

> "*I mean, I would've had extra time in exams... but they didn't set it up until... after Christmas, third year... when I didn't even have exams, so... if it'd being diagnosed earlier, it would have been really different*".(P202/0:33:58)

She contemplated the difference an earlier diagnosis, and being eligible for CSS, would have made to her studies.

> "*Yeah. I think I could've done with some kind of extra time* (in exams) *or something*. (Someone) *specifically ... to help* (with academic studies) *... that would've been good*".(P202/0:45:58)

However, despite this, when describing her greatest emotional achievement, she said, "*I would think...* (greatest achievement was) *.... going and getting a diagnosis and... just because I understand a lot more about myself... Yeah, that's made a big difference*".(P202/01:11:01)

<u>Un-CSS</u> (Evidence of ineffective support practice)

When asked if she had any CSS following her autism diagnosis she said,

> "... (CSS following diagnosis) ... *Not really. I had a mentor, for a while... I got the feeling he was used to working with people who had other disabilities, really. And I got the feeling he didn't really know what to do. And sometimes we'd do, like, he'd just take me to the library and be, like, sit there and do some work... and yeah. It was just really awkward, and then I stopped going*".(P202/0:33:12)

Thus, although she had a '***university funded mentor***', for a short time, she didn't think they were helpful. Karen went on to state that she felt the university had an "*attitude of, like, oh, well, you've nearly finished uni., it doesn't matter what we do*".(P202/0:33:58)

She also expressed that she was too late to apply for additional support through Disabled Student Allowance (DSA).

4.5.6.3 Academic concurrent stressors (Ac-CS)

Academically, Karen described her greatest achievement as, "*getting my degree*".(P202/01:10:04) Hesitantly, she expressed that her initial biggest Ac-CS at university was '**keeping up with the background reading**' and '**speaking in seminar groups in front of her peers**'.

> "*Maybe keeping up with, like, all the reading that we had to do. And...and, like, in seminaries, if they ask you a question … 'cause some of them were quite a big class, and again... like, awkward talking in front of everyone. Public speaking, yeah*".(P202/0:32:07)

Throughout her degree she expressed that she experience Ac-CS due to '**difficulties organising**, **prioritising**, **planning**, **scheduling**, **and structuring her course work so that it wasn't last minute**' and '**difficulties knowing how to start an assignment**'.

> "*Doing course-work, I think, like, timing and... yeah. Planning the course work... not leaving it all to the last minute. I'm still not great at that*".(P202/0:32:48)

> "*Doing work in like an organised kind of manner... I was quite good at researching stuff … but then actually putting it down in course work... Structure, organization … priorities*".(P202/0:51:59)

> "*...sometimes I'd sit down, and I wouldn't really know where to start with it*".(P202/0:43:43)

Lectures also appeared to be a source of Ac-CS for Karen, with her factually stating that she experienced '**difficulties processing what lecturers said in the context of the lecture**'.

> "*Sometimes it was kind of hard to hear what the lecturers were saying in there... It's processing, yeah*".(P202/0:51:04)

She went on to contemplate that if she had an audio device to record lectures and play this back later how this could have helped with her processing difficulties.

> "*…So maybe, like, I could have recorded it or something... and then come back after... I think that would have helped... but I didn't...I didn't think about it at the time*".(P202/0:51:04)

Ac-CSS (Evidence of good support practice)
Karen appeared to received Ac-CSS from her '***lectures***' although this did not appear to be autism specific and she timidly shared that she felt she needed Ac-CSS with '**difficulties organising, prioritising, planning, scheduling, and structuring her course work so that it wasn't last minute**', and '**difficulties knowing how to start an assignment**' CSs. She said at this time she though student services wouldn't help.

> "*Like, I thought...because I'd have to have some kind of special needs diagnosed or something, and at the time, I didn't have any... So, I thought that they probably wouldn't help me*".(P202/0:43:43)

4.5.6.4 Emotional-social concurrent stressors (ES-CS)

The most challenging ES-CS that Karen said she experienced throughout university was '**falling out with her friend who she lived with during her second year resulting in her having to live separate from her friends in her third year**'.

> "*…The whole thing with* 'R'*... 'cause like, I think it would've been better if we didn't live together... Because we … couldn't … get away from it*".(P202/0:38:23)

In a sad tone she described how this resulted in her not being able to live with her friends and having to move back into halls in her third year.

> "*Sometime in second year, I had a big falling out with my friend* 'R'*... and then I was like, I don't wanna live with you next year. So then in third year …back in halls… And then I didn't know the people that I was going to be with*".(P202/0:35:37)

Falling out with her friend appeared to trigger considerable ES-CS such as '**in her third year not seeing her friends from before as much**' and '**not making new friends in her final year**'.

> "*No, not really* (didn't make new friends). *Like, I still saw my friends from before, just not as much ... I kind of got on with my new house mates, but we weren't like close or anything. So yeah, that was different, and I felt like... a bit weird*".(P202/0:36:12)

> "*...I don't know, really, 'cause if I was feeling like really stressed up, I really wouldn't want to talk to anyone about it... Mostly just stayed at my room… Hide from stuff…* (for a) *couple days maybe… wouldn't have asked for it* (support)".(P202/0:48:02)

Karen reflected concern as she shared the CS that worried her the most throughout university, '**fear that she couldn't finish her undergraduate degree**', "*…I guess ... if I couldn't...couldn't finish uni...* (completing your degree) *... Uh-huh*".(P202/0:53:07) As well as experiencing, '**stress due to the academic pressure of deadlines**', such as "*...work stuff as well, like, with deadlines and that, that would be stressful*".(P202/0:38:40)

Timidly she went on to share that she continued to experience '**feeling like she did not fit in with her peers and being social awkward**', describing herself as, "*…still kind of awkward socially*".(P202/0:43:36)

Karen shared that she expected to be more independent at university, make new friends and learn new skills, which she confirmed did happen.

> "*I thought...I thought it was gonna, like...like be more independent... and like, make lots of new friends, and like, I'd learn all kinds of new stuff, and... yeah, I'd say I did*".(P202/0:40:30)

She expressed some positive social experiences from joining the LGBT society, English society, as well as being involved in Brownies and Guides. She described her overall university experience as, "*generally good, kind of stressful, but, well... I guess any uni. would be like that really*".(P202/0:38:10)

ES-CSS (Evidence of good support practice)

Karen shared how ES-CSS continued to be provided by '***Mum***' and '***Dad***' and/or '***close friends***', "…*maybe I'd call home... or friends*".(P202/0:38:55) Karen contemplated that she didn't always deal well with her ES-CS, that additional ES-CSS support, "… *would've been great or something*". (P202/0:47:48) Although in contradiction to this, she indicated that when she was feeling stressed, she was likely to not want ES-CSS, especially to talk to anyone about her ES-CS. She went on to explain that her usual approach to CS was to, "*hide from stuff*".(P202/0:48:24) As mentioned previously Ac-CSS was provided by '***lecturers***' and this would have crossed over into ES-CSS.

4.5.7 Procedural steps 1-2: University (MSc) CTT

4.5.7.1 Emotional-social transitioning concurrent stressors (EST-CS)

Karen worked for nearly two years in a local supermarket following her undergraduate degree. She stated that she was excited to return to university where she would have the opportunity to be, "*studying something new 'cause... I switched to...to doing computer science... with the conversion course, then yeah, I was just excited to start that*".(P202/0:56:16). The first time Karen visited the university, where she was going to do her MSc, was during an open day when she, "*…spoke to some of the lecturers about, like, what the course would be like... and that was good*".(P202/0:54:04) Smiling she stated that she then returned to this university for an autism two-day orientation event, where she met some peers, stayed in halls and had a tour of the campus.

> "*…we had the orientation thing for eureka* (students with autism) ... *I came to the...the two-day thingy. I liked meeting some other people...other students… we stayed in halls, and that kind of, reminded me like okay… I could do independent living… and got me thinking about, like, what it would be like being back at uni.... just generally being around the campus and everything*".(P202/0:55:26)

Prior to starting Karen hesitantly shared her dominant EST-CS, '**fear about living independently**', '**fear about living with new people**' and '**fear about returning to academic studies**'.

> "(most scared of) *...Independent living and going back to, like, academic, like, studying and things... yeah, using my brain …*(laughs)*… moving away, I think, meaning to somewhere that I didn't know... and living in halls with...with the new people*".(P202/0:55:26)

She shared how she '**worried that she wouldn't be able to keep up with the course and do the exams**'.

> "*If I cannot keep up with the course, I guess. Because I've been out of practice, like, doing, like, exams*".(P202/0:56:33)

> "*They had a lot more support than what I expected to have… Well, it was good… definitely. It was helpful. Because if it was like, you're not the only one with, if you are feeling stressed about... about of coursework, or just uni. in generally... then you don't feel so different as well 'cause... it feels like there's... the uni. has people who know about autism*".(P202/0:58:19)

She timidly shared that she experienced '**greater CS starting her MSc compared with what she felt starting her BSc**'.

> "*It was more, kind of...I'm not sure what the right word is... I was far more stressed about it than when I was starting in* '*previous university*' *... I think it just took me a while to...to settle in*".(P202/01:05:41)

> "*I went to the wellbeing thing. And then I got set up mentoring … and that... with the DSA. And then Eureka group. I would probably talk to my mentor,* 'T' *… and try and do something before it escalates*".(P202/01:07:57)

EST-CSS (Evidence of good support practice)
In terms of EST-CSS, as mentioned earlier, the university ran an '***open day***' which provided her with an opportunity to '***speak to lecturers***' *and a* '***two-day orientation event***' where she met fellow peers, had a '***tour of the campus***', and '***stayed overnight***'.

4.5.7.2 Academic concurrent stressors (Ac-CS)

Laughing Karen reminisced about the first week of her MSc, "*… I remember the first lecture, and going in I was really, like, oh, look at me in a lecture thing I was so excited* (laughs)".(P202/0:59:10) She expressed her Ac-CS moving on to a MSc, '**that it was a big academic jump**' and '**adapting to a fact-based course**', which was different to her undergraduate degree.

> "*... quite big* (academic) *jumps at some point...parts in the course. Like with the programming when we were doing Java*". ... "*Adjusting to the...the different...the different style, of course. Because, like, it's a lot more facts-based with computer science than in* 'undergraduate uni.'*… and that's been, kind of, stressful getting... getting used to that*".(P202/01:06:45)

<u>Ac-CSS</u> (Evidence of good support practice)

However, she went on to explain that Ac-CSS was provided by '***lecturers***' and her '***department***', when they put on '***extra classes***', "*… for Java... so that was good…*", and when they gave her deadline '***extensions***' for "*…coursework's over the Christmas break*".(P202/01:00:47) Since she now had an autism diagnosis, she also received DSA '***specialist autism mentor***' Ac-CSS and ES-CSS.

> "*… mentoring and* 'mentor' *helps with, like, we look at my coursework and what things I have coming up. And then... we draw a little plan of, like, how I'm gonna do them and what I have to do for, like, each assignment... and when and that kind of thing. That's useful. Yeah...yeah. That's from the DSA*".(P202/01:01:22)

4.5.7.3 Emotional-social concurrent stressors (ES-CS)

Karen was concerned '**that the university might think less of her due to her autism diagnosis**' and/or '**that the university might think she shouldn't be in university due to her autism diagnosis**'.

> "*I thought it was a little bit awkward. Just, like, I didn't want whoever read that application to see it and think that...that I couldn't do things... I just worried that they might think less of me when they saw that I had ASD because... Just I wouldn't be able to be in university, I guess*".(P202/0:56:58)

Socially Karen described her greatest achievement as, "*... I guess, coming to uni, both times ... because they've been, like, a whole new place... and I didn't know anyone*".(P202/01:10:21) In a contemplative tone, Karen explained that it was, "*… a long time to, like, get used the people I was living with*". Although, she did share that by this point in time she did feel, "*... more confident socially, I didn't feel so much like I absolutely have to fit in with people. So less nervous*".(P202/01:01:59) She described her biggest '**social**' CS as, '**finding it difficult to make friends with peers on her course**', "*… because it's easy to just get in, like...get into sitting and doing your lecture notes and that and...leave*".(P202/01:03:48) This CS appeared to be alleviated by her department who encouraged social interaction opportunities amongst computer science peers, "*... I did this Google challenge thing. And then you do that in a team with other people… So yeah, there's been things like that, where you can get to know people*".(P202/01:04:12)

ES-CSS (Evidence of good support practice)

‘***Departmental***’ CSS provided Karen with social opportunities to meet with fellow computer science peers. ‘***Eureka peers***’ (autism social group), ‘***close friends***’, and her ‘***specialist autism mentor***’, provided Karen with ES-CSS. ‘***Mum***’ and ‘***Dad***’ continued to provide her with ES-CSS, with her calling, “… *home* …(to)…*talk about it* (CS)”.(P202/01:06:07) Although, she stated that in general emotionally, during her MSc she was, “… *good*…”.(P202/01:06:37) Prior to starting her MSc, Karen shared that she was aware that the university had ‘***wellbeing***’, ‘***ASC service***’ ES-CSS, “… *well-being* (ES-CSS), *and then the autism thing* (Eureka)”. She went on to state that she was surprised by the amount of ES-CSS available to her as she had thought that this ES-CSS would be, “… *more of, like, an occasional thing, than what it actually was... like, it would just kind of be there, and I would maybe go and talk to someone if I wanted*”.(P202/0:57:52)

4.5.8 Procedural step 3

The categorical-form analysis (CFA) of Karen’s data enabled me (the researcher) to gain in-depth insight into her linguistic dialogue, namely her tones of voice and non-verbal communication. This was performed by using Karen’s fabula notes and tagging frequency of nonverbal (sjuzet) occurrences within her narrative statements, using reflective diary entries. CFA data was categorised into fourteen varied tones, and non-verbals, and frequencies calculated. CFA data relating to Karen’s state of health, positive and negative tones, and non-verbals (n=8), were then used to illustrate tonal frequencies within her narrative. Table 4.2 (c) details fabula notes and tagged positive and/or negative nonverbal calculation for each CTT, which will be discussed in more detail in next sections (appendix 4.2 (a) details a breakdown of these calculations).

Table 4.2 (c): The positive and negative linguistic tones and nonverbals used by Karen during her interviews that were identified using the sjuzet data applied to statements made within the context of themes and subthemes.

		Percentage category occurrence of positive and negative linguistic tones/nonverbals in each CTT				
Tone or non-verbal used (frequency)	**Category (frequency)**	**Primary**	**Secondary**	**Sixth form**	**University**	**University**
gesturing & tapping hands (78) friendly (45) smiling/laughing (30) positive (25) happy (22) positive & open communication (78)	**Positive** (250*)	9%	18%	19%	>positive 29%	25%
twisting hands (5) sad (3)	**Negative** (7**)	14% (25% of the total ‘Twisting hands’ tone used in this CTT) (Sad 0)	>negative 43% (75% of the total ‘Twisting hands’ tone used in this CTT) (Sad 0)	14% (Twisting hands 0) (33% of the total Sad tone used in this CTT)	29% (Twisting hands 0) (67% of the total Sad tone used in this CTT)	0% Twisting hands (0) Sad (0)

*Positive (28 tones did not relate specifically to a CTT and have been excluded) (Total tones n=6)
**Negative (1 twisting hands tone did not relate specifically to a CTT and has been excluded) (Total tones n=2)

NB: Not included in this table were factual, contemplative, serious, timid, ‘other’ (hesitant, playing with hands) (Total tones n=6)
>Indicates the greatest frequency of tone type occurrence amongst all the CTTs

4.5.9 Procedural step 4

Holistic-form analysis (HFA) combined HCA, CCA, CFA results, using the HFA scoring matrix (chapter 3, section 3.6.6.3, table 3.3), to produce an HFA numerical score that could then be attributed to a CTT (calculation shown in appendix 4.2 (b)). This score was then compared with another CTT to gauge Karen's narrative progression or regression. HFA score also enabled consideration of the structure of Karen's narrative, how she positioned herself within it, her typology, cohesion within her narrative and any turning points. The 'overall' core of Karen's transitioning story showed a stable, regressive, then progressive, narrative (figure 4.2 (a)). The limitations of using a scoring matrix are discussed in section 6.7.

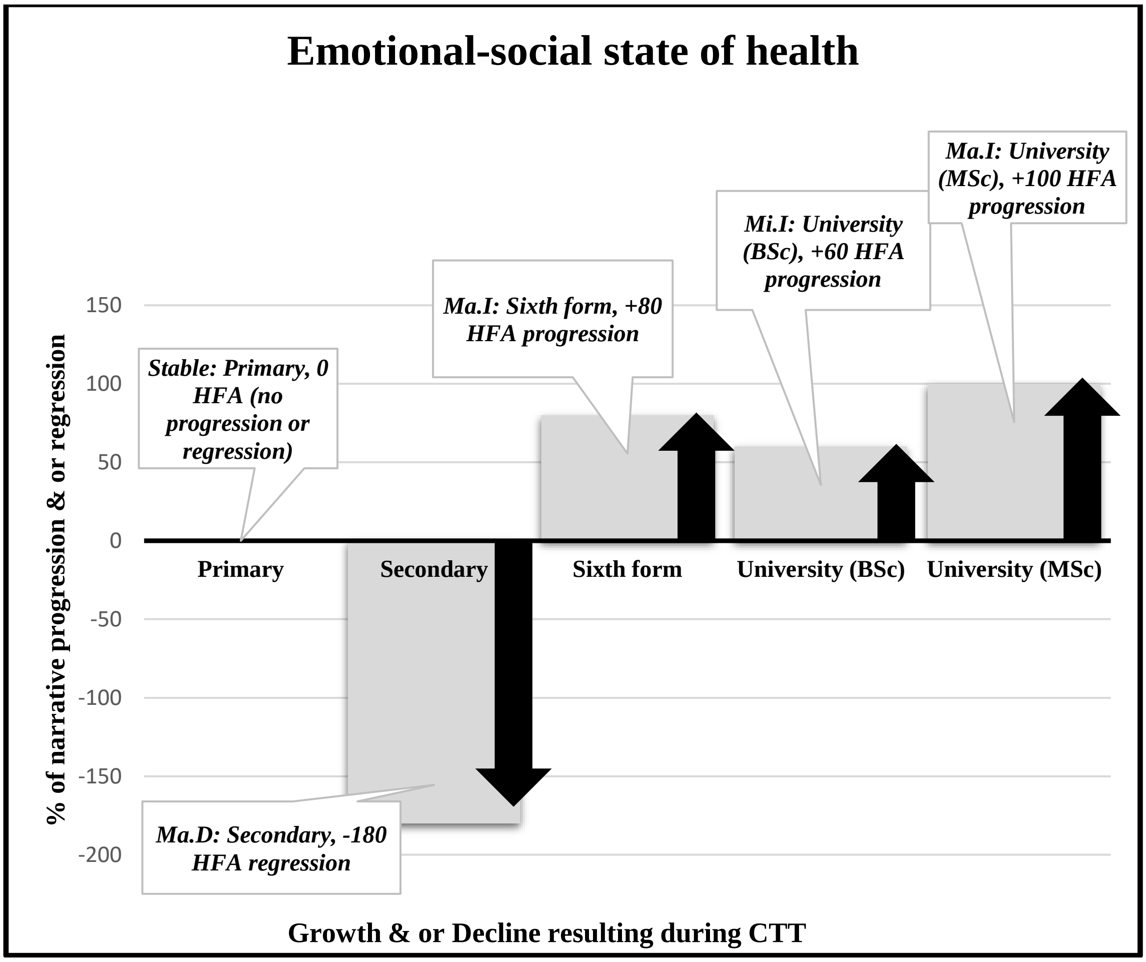


Figure 4.2 (a): Holistic-form: Narrative regression and progression of Karen's Core Story, CTT, TST, in relation to state of health. MiD = Minor deterioration in state of health / MaD = Major deterioration in state of health / MiI = Minor improvement in state of health / MaI = Major improvement in state of health

The primary CTT demonstrated a zero HFA score, a stable narrative and state of health due to no mention of ES-CS (figure 4.2 (a) column 1).

The secondary CTT demonstrated -180 HFA regressive narrative decline (figure 4.2 (a) column 2). This CTT had the greatest occurrence of CFA minor negative-twisting hands nonverbal when discussing Ac-CS, ES-CS, EST-CS, and CSS experiences, compared with other CTT (table 4.2 (c)). This tone was classified as a minor negative CFA tone and is thus suggestive of a negative experience. Karen's data indicated that she experienced a major deterioration in state of health (MaD) during this CTT. This secondary CTT appeared to be a major negative turning point for Karen, due to increased ES-CS, '**social anxiety**' and '**social**'.

The sixth form CTT demonstrated +80 HFA progressive narrative growth (figure 4.2 (a) column 3). Karen's data indicated that she experienced a major improvement in state of health (MaI) during this CTT, due to no new or ongoing ES-CS, implying that she overcame previous CS or that these were considerably reduced. This CTT, appeared to be a major positive turning point for Karen, likely to be due to improved ES-CS experiences.

The university (BSc) CTT demonstrated +60 HFA progressive narrative growth (figure 4.2 (a) column 4). This CTT had the greatest occurrence of CFA major positive tones, discussing Ac-CS, ES-CS, EST-CS, and CSS experiences, compared with other CTT (table 4.2 (c)). Thus, Karen's data indicated that she experienced a minor improvement in state of health (MiI) during this CTT, evidenced by her overcoming or a reduction previous ES-CS, and a second year minor ES-CS incident that she was able to resolve.

The university (MSc) CTT demonstrated +100 HFA progressive narrative growth (figure 4.2 (a) column 5). Karen's data indicated that she experienced a major improvement in state of health (MaI) during this CTT. This was likely to be due to Ac-CSS and ES-CSS that accompanied her autism diagnosis (aged 20 years), no mention of ES-CS, implying that he overcame previous CS or that these were considerably reduced, and an overall improvement in ES-CS experiences.

4.5.9.1 Karen’s typology

HFA revealed that Karen’s typology was a mix of ‘resilient-perseverance’ throughout her narrative. Karen’s presented herself as an individual who faced ES-CS with the resilience to not only endure ES-CS but also an innate strength to overcome ES-CS quickly when it was possible for her to do so. When it was not possible for Karen to overcome her ES-CS in a CTT, she demonstrated perseverance by not giving up emotionally-socially and by being optimistic when faced with ES-CS experiences in her next CTT. Typology will be discussed in detail in step 6, section 4.5.11.

Table 4.2 (d): Calculation of Karen’s Holistic-form analysis score combining HCA, CCA, CFA narrative data. HCA = holistic-content analysis, CCA = categorical-content analysis, CFA = categorical-form analysis, HFA = holistic-form analysis, CTT = core transitioning theme, CS = concurrent stressor, Ac = academic, ES = emotional-social, MiD = minor deterioration to state of health, MaD = major deterioration to state of health, MiI = minor improvement to state of health, MaI = major improvement to state of health

	Holistic-form analysis frequency and score									
	Primary		**Secondary**		**Sixth form**		**University (BSc)**		**University (MSc)**	
(i) Previously identified CS	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**
Major Ac-CS (impacting state of health) $(f\ x\ -5)$	-	-	f = 1	n = - 5	-	-	f = 1	n = - 5	-	-
Minor ES-CS $^{(f\ x\ -5)}$	-	-	f = 6	n = - 30	-	-	f =3	n = - 15	-	-
Major ES-CS $^{(f\ x\ -10)}$	-	-	f = 2	n = - 20	f = 2	n = - 20	f = 2	n = - 20	-	-
(ii) CFA linguistic (nonverbal) results	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**
Minor negative CFA $^{(f\ x\ -25)}$	-	-	f = 1	n = - 25	-	-	-	-	-	-
Major negative CFA $^{(f\ x\ -50)}$	-	-	-	-	-	-	-	-	-	-
Minor positive CFA $^{(f\ x\ +25)}$	-	-	-	-	-	-	-	-	-	-
Major positive CFA $^{(f\ x\ +50)}$	-	-	-	-	-	-	f = 1	n = +50	-	-
(iii) State of health	**Category (HFA total score)**		**Category (HFA total score)**		**Category (HFA total score)**		**Category (HFA total score)**		**Category (HFA total score)**	
MiD $^{(f\ x\ -50)}$	-		-		-		-		-	
MaD $^{(f\ x\ -100)}$	-		n = -100		-		-		-	
MiI $^{(f\ x\ +50)}$	-		-		-		n = + 50		-	
MaI $^{(f\ x\ +100)}$	-		-		n = + 100		-		n = +100	
	Total primary HFA score		**Total secondary HFA score**		**Total sixth form HFA score**		**Total university (BSc) HFA score**		**Total university (MSc) HFA score**	
	n = 0 (stable narrative)		n = - 180 (regressive narrative decline)		n = + 80 (progressive narrative growth)		n = + 60 (progressive narrative growth)		n = + 100 (progressive narrative growth)	

4.5.10 Procedural step 5

To be able to illustrate to the reader Karen's ability to adapt to a CTT, I encompassed Karen's HCA, CCA, CFA, HFA data into the 'educational transitioning model', which visually detailed; (1) any CS that impacted her state of health, (2) 'self' characteristics, (3) concurrent stressor support (CSS), (4) previous CTT state of health compared with current state of health. The educational transitioning models (figures 4.2 (b)-(f)) summarise Karen's lived experiences and educational journey in relation to her state of health.

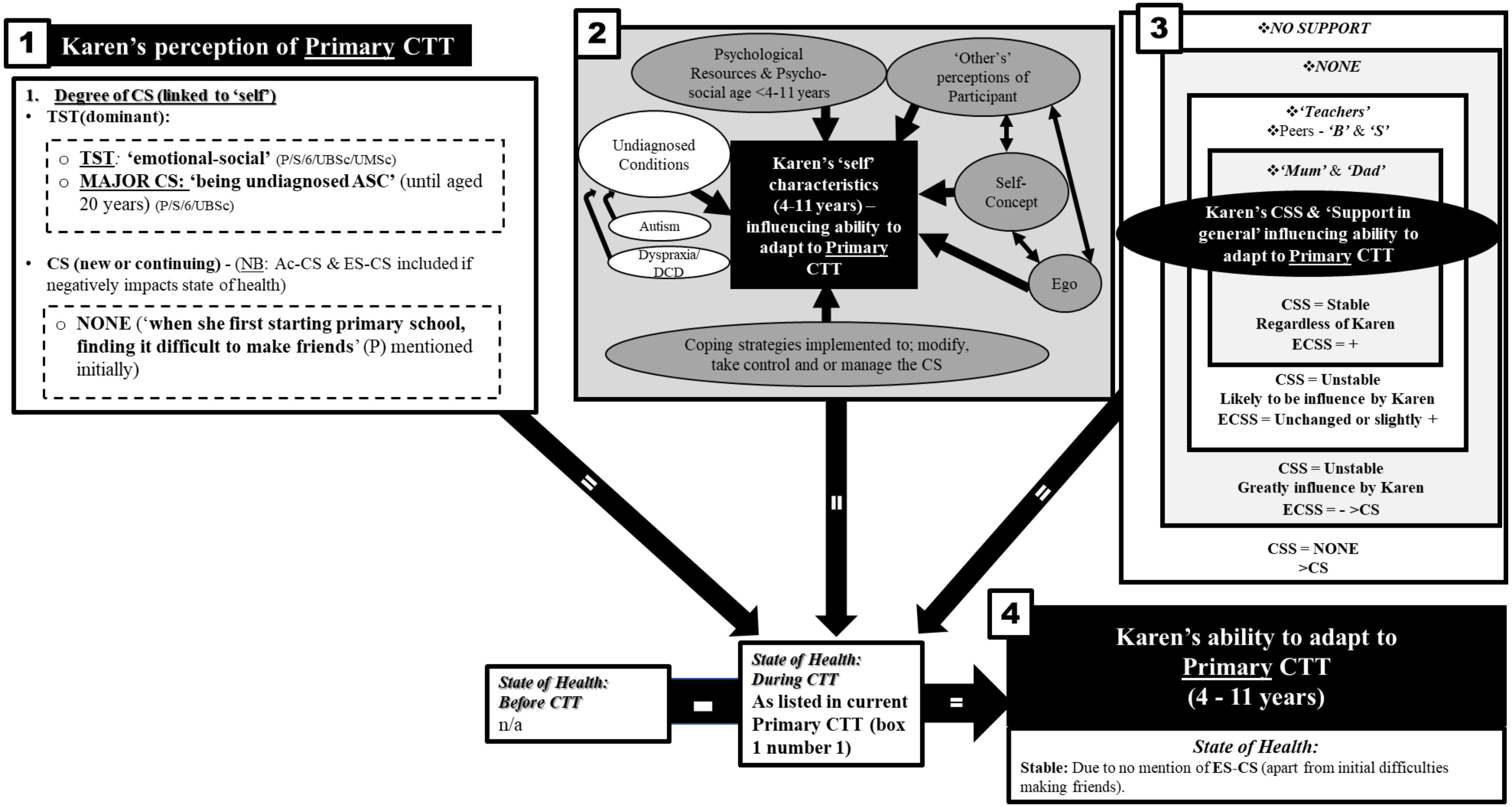


Figure 4.2 (b): Educational transitioning model representing Karen's ability to adapt to the primary CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

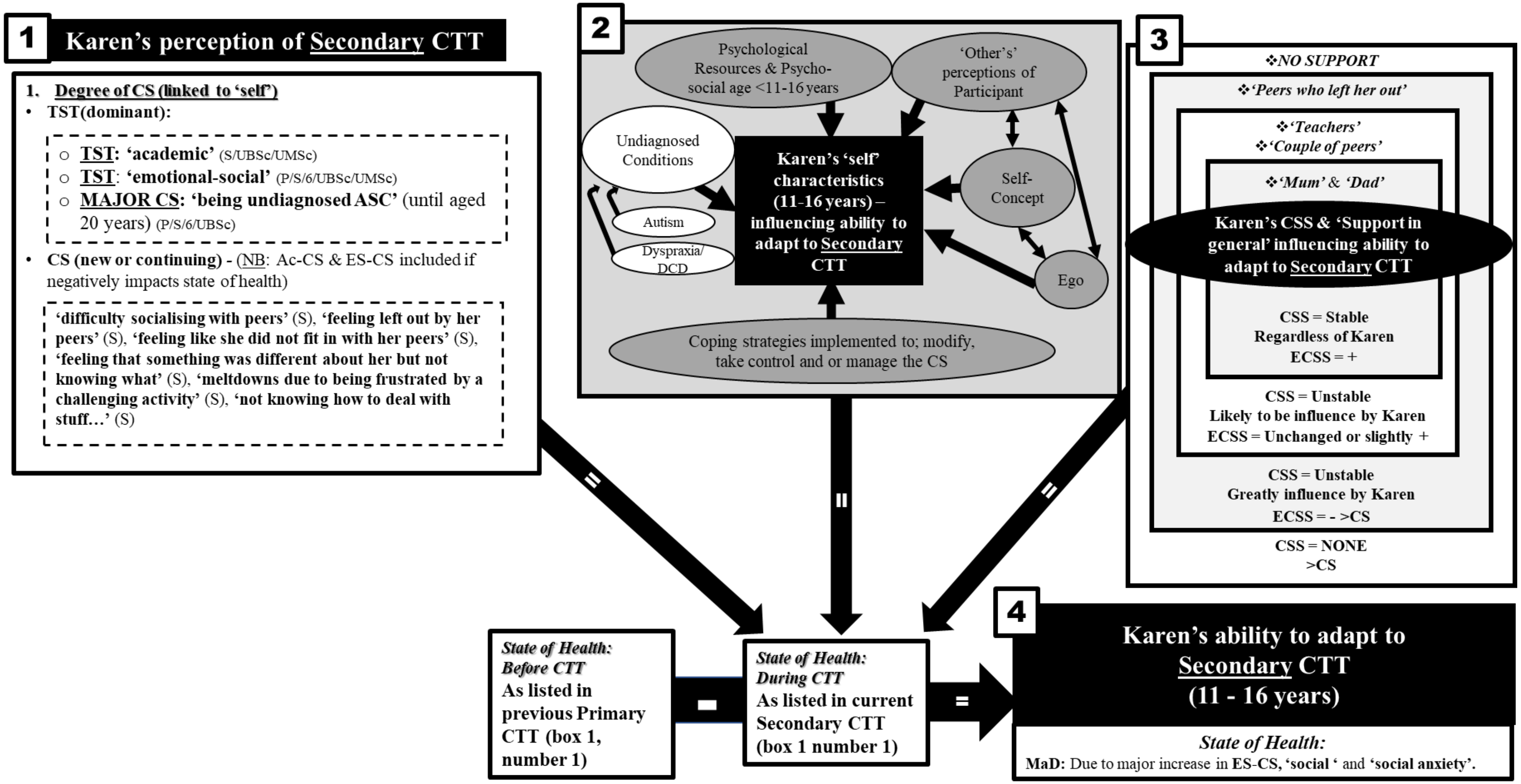


Figure 4.2 (c): Educational transitioning model representing Karen's ability to adapt to the secondary CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268]

For abbreviations see chapter three, table 3.4.

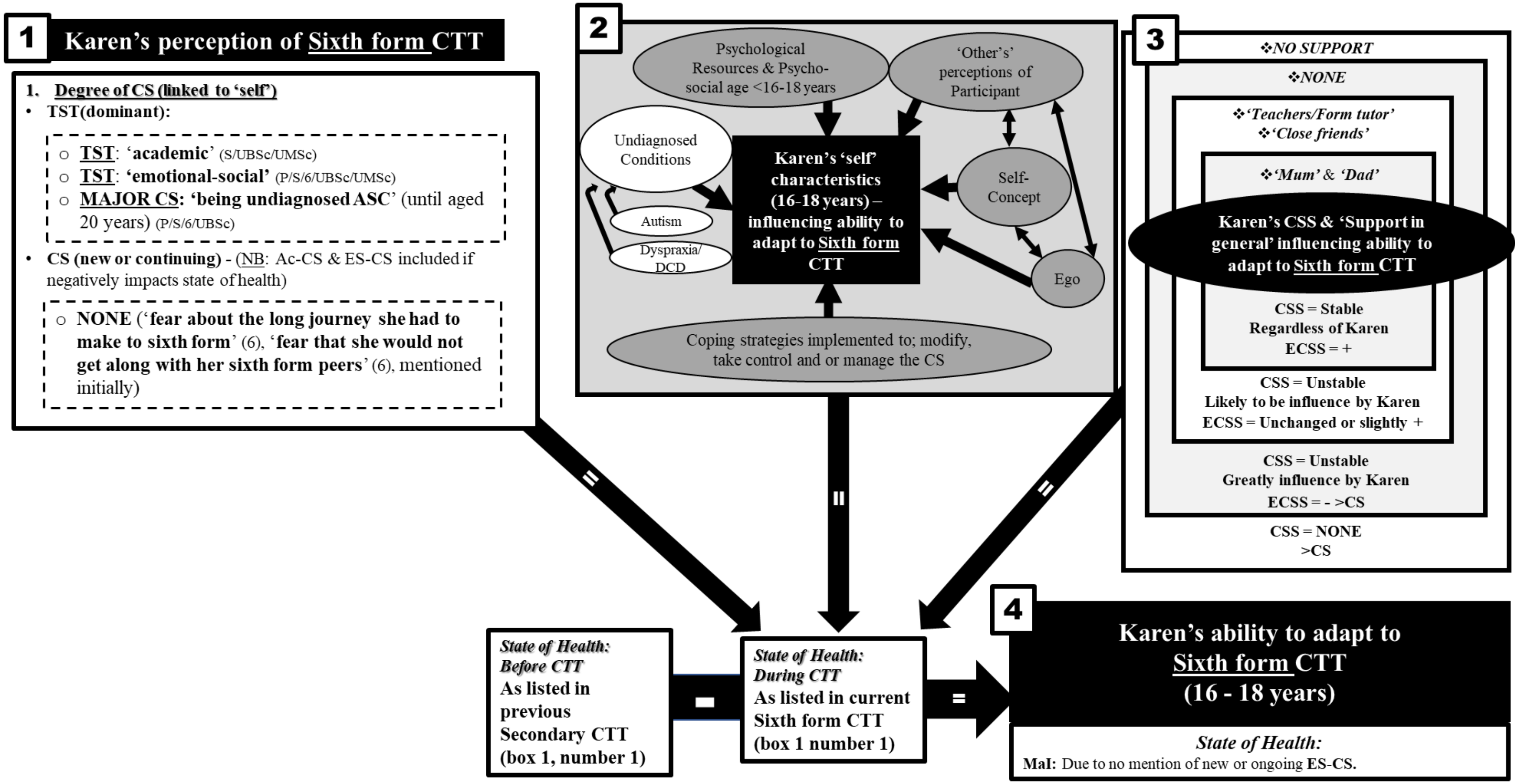


Figure 4.2 (d): Educational transitioning model representing Karen's ability to adapt to the sixth form CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268]
For abbreviations see chapter three, table 3.4.

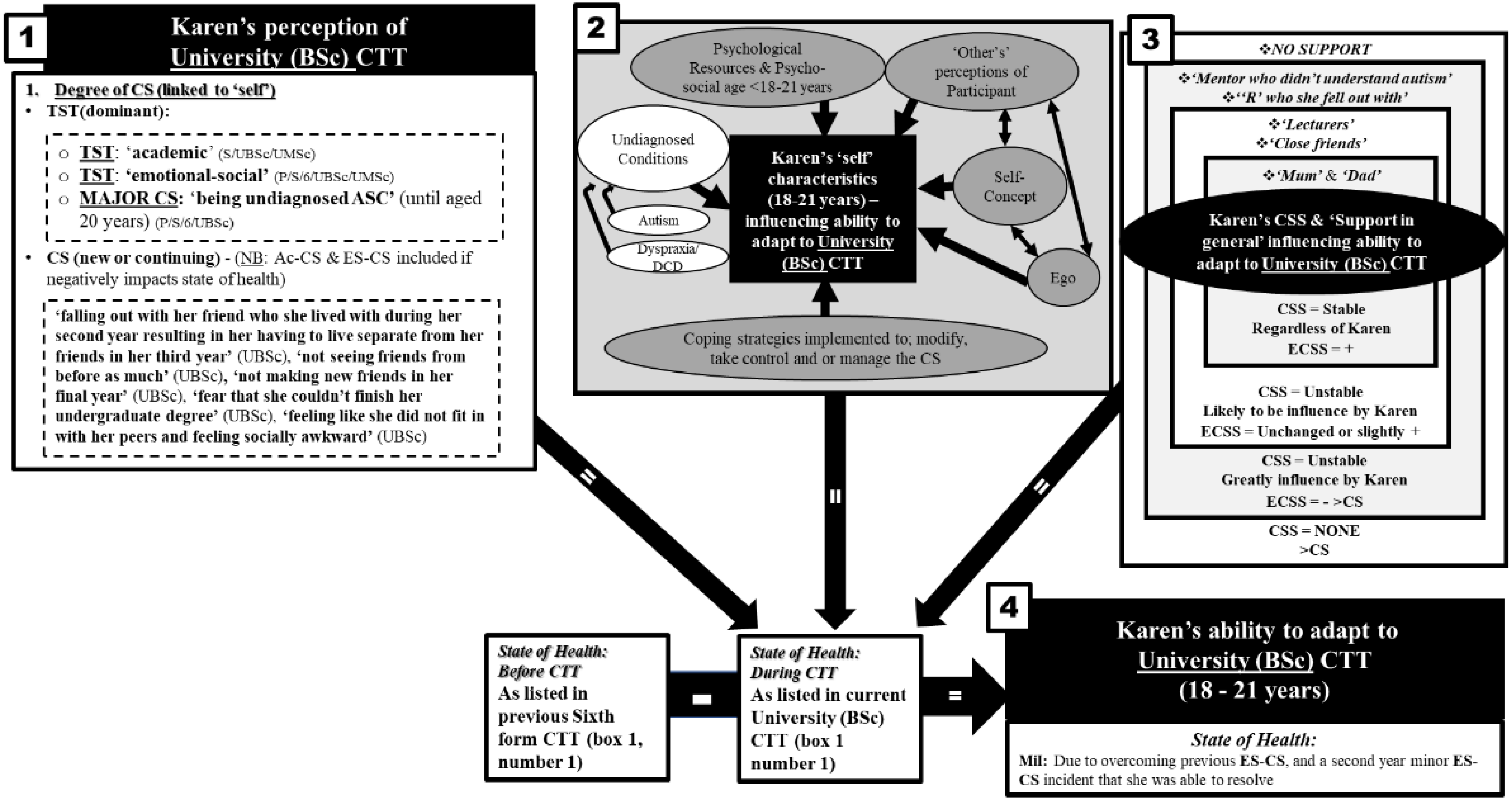


Figure 4.2 (e): Educational transitioning model representing Karen's ability to adapt to the university (BSc) CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

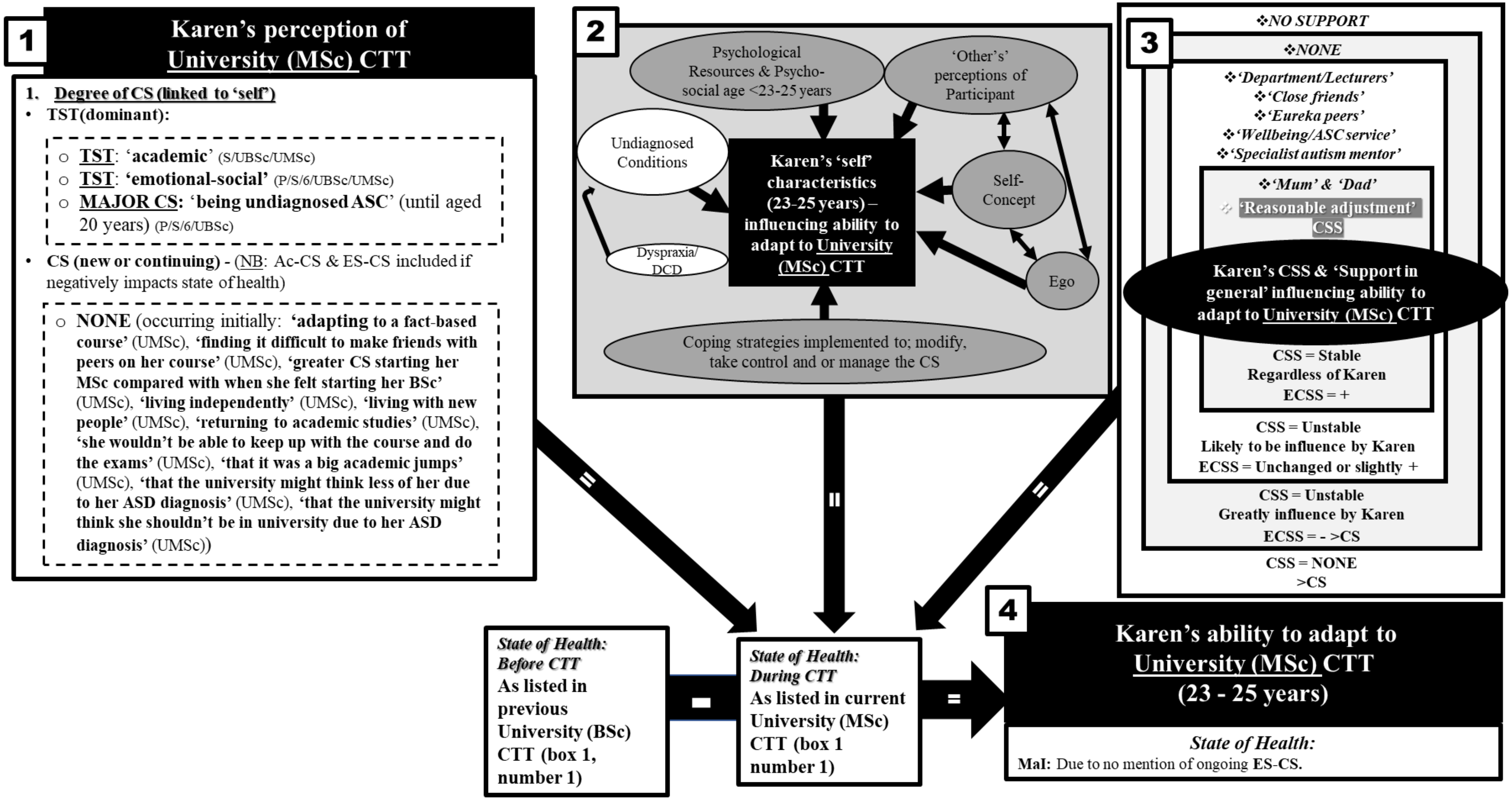


Figure 4.2 (f): Educational transitioning model representing Karen's ability to adapt to the university (MSc) CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

4.5.11 Procedural step 6

Critical narrative analysis (CNA) considers the functionality of Karen’s story, how she is positioned within it, by considering the fabular and sjuzet properties reflecting her; thoughts, feelings, emotions, actions, interactions, achievements, challenges, and the social structure in which her story takes place. CNA identified a critical positioning theme; namely Karen as a ‘resilient-persevering’ typology.

4.5.11.1 Karen’s positioning as a ‘resilient-persevering’ typology

In the secondary CTT, Karen experienced a major deterioration in her state of health (MaD) due to ES-CS. During this secondary CTT Karen demonstrated the positive development of resilience skills, that she was able to endure these CS and to overcome them, and that they did not continue into the next sixth form CTT. She demonstrated perseverance by not giving up and letting these secondary CTT CS influence her ability to form emotional-social friendships in her next CTT. The university BSc CTT is another example of her positioning, when she experienced a minor deterioration in her state of health (MiD) due to a major ES-CS, ‘**falling out with her friend who she lived with during her second year resulting in her having to live separate from her friends in her third year**’. Regardless of this CS, Karen demonstrated further resilience skills at this time, through her innate strength to overcome this ES-CS by deciding to live back in university halls in her third year. She demonstrated perseverance by continuing to maintain previous friendships and by proactively experiencing new emotional-social interactions, undeterred by previous ES-CS experiences.

4.5.12 Summary of Karen's ability to adapt to each core transitioning theme

HCA: CTT; primary, secondary, sixth form, university (BSc), university (MSc).
CCA: TST; academic (Ac), emotional-social (ES).
CFA: Greatest occurrence of minor negative nonverbal, twisting hands, during secondary CTT. Greatest occurrence of major positive tones during university (BSc) CTT.
HFA: Indicated a stable, regressive-progressive narrative.
HFA & CNA: HFA linguistical analysis and CNA revealed a 'resilient-persevering' typology. Resilient during the secondary CTT and university (BSc) CTT when faced with major CS. Persevering throughout all CTT to form ES friendships undeterred by ES barriers.

HCA, **CCA**, **CFA**, **HFA**, **combined (table 4.2 (d)):**
Primary CTT, evidences a stable narrative. Evidence of good support practice took the form of: Stable CSS (regardless of behaviour) was provided by '***Mum***' and '***Dad***', unstable positive CSS (influenced by behaviour) from peers '***B***' and '***S***' and '***teachers***'. Data indicated a stable state of health evidenced by no mention of ES-CS.
Secondary CTT, evidences a regressive narrative. This CTT had the greatest overall HFA narrative regression, compared with other CTT. This CTT had the greatest occurrence of CFA minor negative-twisting hands, suggestive of negative experiences, compared with other CTT. Evidence of good support practice took the form of: Stable CSS continued to be provided by '***Mum***' and '***Dad***', unstable positive CSS was provided by a '***couple of peers***' and '***teachers***'. Data indicated a major deterioration in state of health evidenced by a major increase in ES-CS, '**social anxiety**' and '**social**'.
Sixth form CTT, evidences a progressive narrative. Evidence of good support practice took the form of: Stable CSS continued to be provided by '***Mum***' and '***Dad***', unstable positive CSS by '***teachers***', '***form tutor***' and '***close friends***'. Data indicated a major improvement in state of health evidenced by no new or ongoing ES-CS, implying that she overcame previous CS or that these were considerably reduced.

University (BSc) CTT, evidences a progressive narrative. This CTT had the greatest occurrence of CFA major positive tones compared with other CTT. Evidence of good support practice took the form of: Stable CSS continued to be provided by '***Mum***' and '***Dad***', unstable positive CSS was provided by '***lecturers***' and '***close friends***'. Data indicated a minor improvement in state of health evidenced by her overcoming or a reduction in previous ES-CS, and a secondary year minor ES-CS incident that she was able to resolve.

University (MSc) CTT, evidences a progressive narrative. Evidence of good support practice took the form of: Stable CSS continued to be provided by '***Mum***' and '***Dad***', unstable positive CSS was provided by '***department***', '***lecturers***', '***close friends***', '***Eureka peers***', '***Wellbeing/ASC service***', and her '***specialist autism mentor***'. '***Reasonable adjustments***' CSS were put in place. Data indicated a major improvement in state of health evidenced by no mention of ongoing ES-CS, implying that she overcame previous CS or that these were considerably reduced, likely to have been help by increased Ac-CSS and ES-CSS, due to having an autism diagnosis (aged 20 years).

4.6 Jane’s story

4.6.1 Background and setting

The initial participant interview with Jane took place in her current university in a private lounge area. At the time of the interview, Jane was in the second year of her history degree.

4.6.2 Procedural steps 1-2: Overview

The holistic-content analysis (HCA) of Jane’s data is reflected in table 4.3 (a), the core transitioning themes (CTT) that emerged from her educational journey narrative. Two overarching TSTs were identified, namely ‘**academic**’ (Ac) and ‘**emotional-social**’ (ES). The ‘**emotional-social**’ (ES) subtheme has been grouped to include CS related to this heading such as; bullying, discrimination, friendship, group interactions, mental health (e.g., anxiety, fears, phobias, self-harm, stress), social anxiety, stigma, and so on.

Table 4.3 (a): Holistic-content analysis overview: Jane’s core transitioning themes (CTT) and transitioning sub-themes (TST). Her age during each CTT is indicated within the brackets.

	Core transitioning themes (CTT)				
	Primary (infant) (4-7 years)	**Primary (junior) (7-11 years)**	**Secondary School (11-16 years)**	**Sixth form (16-19 years)**	**University (BSc) (19-21 years)**
Transitioning sub-themes (TST)	Academic (Ac) Emotional-Social (ES)				

The categorical-content analysis (CCA) of Jane’s data, enabled a more in-depth examination of each CTT to look for patterns. For each CTT, Jane’s narrative was examined for the appearance of the specific concurrent stressors (CS) experienced by her (table 4.3 (b)) with the sections that follow giving context and describing them in detail. In the primary (infant and junior) and secondary CTTs their appearance appeared to be exacerbated by the overarching or major ES-CS ‘**being undiagnosed ASC**’ which was likely to have had impacts on both the ‘**academic** ‘ (Ac) CS and ‘**emotional-social**’ (ES) CS.

Table 4.3 (b): Categorical-content analysis overview: Jane’s transitioning sub-themes (TST) and concurrent stressors (CS). Table also shows the core transitioning themes (CTT) or timepoints where the CS occurred. I = infant (primary), J = junior (primary), S = secondary, 6 = sixth form, U = undergraduate university

Transitioning sub-themes (TST)	**Concurrent stressors (CS)**	**Time point(s)**				
		I	**J**	**S**	**6**	**U**
	Major CS: ‘being undiagnosed ASC’ (until aged 16 years) **(Un)**	I	J	S		
	Major CS: ‘sensory challenges’ (SnC)	I	J	S	6	U
‘academic’ (Ac)						
	‘academic jump from GCSE to A-level’				6	
	‘difficulties with English language’	I	J	S		
	‘doing historical analysis’					U
	‘falling behind in English’		J			
	‘greater academic demands’	I				
	‘Historiography’				6	
	‘lacking the ability to write legibly’	I				
	‘lacking the foundations of math’					U
	‘less geography and history classes’			S		
	‘struggle with academic deadlines’					U
‘emotional-social’ (ES)						
	‘anorexia’		J	S	6	
	‘anxiety’	I	J	S	6	U
	‘argument with flatmates during first term’					U
	‘being alone’			S		
	‘being bullied’	I	J	S		
	‘being forced to socialise’	I	J			
	‘being labelled as a problem child’		J			
	‘being refused entry into the SEN unit’			S		
	‘belief she was different to her peers’	I				
	‘confusion at being put into exclusion (isolation)’			S		
	‘difficulties with social relationships with girls’			S		
	‘discrimination against her family by her teachers’			S		
	‘emotional mental health’			S		
	‘fear of change’					U
	‘feeling like the odd one out’		J			
	‘having a meltdown’				6	U
	‘living in university accommodation’					U
	‘loneliness’					U
	‘meeting new people’					U
	‘others stereotypical views of autism’				6	
	‘Parent screaming in her face’		J			
	‘people bitching and talking behind her back’				6	
	‘reminiscing about the way she had been treated previously in school’				6	
	‘self-harming’			S	6	
	‘social difficulties’	I	J	S	6	U
	‘social exhaustion’				6	
	‘social vulnerability’					U
	socialising’		J			
	‘stress’				6	
	‘struggled with her autism diagnosis in general’				6	
	‘suicide attempts’			S		
	‘teacher’s negative behaviours towards her’		J	S		
	‘trichotillomania’	I	J	S		
	‘trying not to be too weird’					U
‘emotional-social transitioning’ (EST)						
	‘apprehensive due to the social upheaval’			S		
	‘struggled to readapt to sixth form college’				6	

4.6.3 Procedural steps 1-2: Primary (infant) CTT

4.6.3.1 The major concurrent stressor 'being undiagnosed ASC' (Un-CS)

Jane started the interview excitedly recalling her mum telling her that she suspected something was different about her when she was six months old.

> "*Okay. So, when I was born, my mum said in about six months she could realise I was different, like, I could never make eye contact… at the age of three...and the age of five, the school nurse came into school, but both times told my mum not to get a diagnosis because...get an autism diagnosis because it would hinder me in life*".(P203/00:00:43)

During this CTT Mum recalled how she requested that the school referred Jane for an assessment, due to an array of ES-CS, only to be told by the school nurse that "*she didn't have anything wrong, very good, do nothing*".(PFM203/00:00:57) Jane sadly and factually explained other reasons as to why mum did not pursue her autism assessment during this CTT as being due to, "*people and stigma … as … my mum thought because she hadn't given me the … 'MMR*' (measles, mumps, rubella immunisation). *That there was no possible way I could have had autism… which meant I was very late to be diagnosed*".(P203/00:02:24)

4.6.3.2 The major concurrent stressor 'sensory challenges' (SnC-CS)

'**Sensory challenges**' (SnC-CS) were recalled, how she "*hated loud noises*",(P203/00:19:03) which resulted in Ac-CS and ES-CS. Jane appeared particularly distressed by the noise levels in infant school, "*people, liked, making a loud noise, screaming. Obviously, the school hall. Just...just now and again- we used to have the old lift up desks and when people slammed the desk down that would really, really, really, like, get to me*".(P203/00:19:19)

No SnC-CSS

Jane didn’t receive any additional support, or SnC-CSS from school, verified by Mum who was told by others that Jane was ‘just making a fuss’.

> “*... Jane didn’t like noises. We could never go to firework displays… she used to go absolutely hysterical and obviously we didn’t realise why, and she didn’t like loud noises and bangs, but people used to just say she was making a fuss*”.(PFM203/00:03:26)

4.6.3.3 Academic concurrent stressors (Ac-CS)

Jane’s Ac-CS often manifested in ‘**difficulty with English language**’ CS, and these struggles continued in her junior school years. Transitioning into infant school appeared to result in CS due ‘**greater academic demands**’ being placed on her. She expressed disappointment in her academic abilities to meet the increasing demands in her English lessons, she “*struggled with …English*”,(P203/00:10:58) placing blame on her belief that she, “*had never been taught properly*”,(P203/00:11:10) and she reasoned that this was why she ultimately ended up with a low English Language GCSE grade of “*E, or an F grade*”.(P203/00:11:05) Jane also appeared to experience Ac-CS due to ‘**lacking the ability to write legibly**’, which was mentioned by Mum on a couple of occasions.

> “*They said she didn’t hold her pencil right, so they bought her some of those rubber things that you could put on your pencil*”,(PFM203/00:00:57) and Mum also mentioned that Jane’s “*writing was scruffy*”.(PFM203/00:11:08)

Ac-CSS (Evidence of good support practice)

Jane stated that the Ac-CSS provided by ‘***teachers***’ in infant school was either limited or non-existent, stating in a serious tone that she “*didn’t have any*”.(P203/00:13:14) Positive ‘self’ characteristics displayed by Jane in infant school that potentially alleviated her Ac-CS was her self-belief that she “*had … strengths and weaknesses*”(P203/00:11:30) and she recognised that she “*was always sort of clever*”.(P203/00:10:43) She mentioned having strengths in subjects such as “*math and science*”(P203/00:10:52) and, as proudly stated by Jane, in “*geography and history … my specialism from a very young age...at the age of, like, five I could name all the continents*”.

4.6.3.4 Emotional-social concurrent stressors (ES-CS)

Jane suffered ES-CS, a '**belief she was different to her peers**', "*you know you're different… but you don't know why you're different*".(P203/00:17:25) This was verified by Mum who shared that Jane "*said she knew when she was seven that she was different to everybody else*".(PFM203/00:12:30) Jane also shared ES-CS due to having '**anxiety**', '**being bullied**' and stated her belief that these CSs triggering '**trichotillomania**' CS.

> "*Yeah. I mean, the bullying started in infant school. I mean, I... I knew I was different. I started pulling my hair out at the age of about 4 or 5. I had trichotillomania from the ages of about 4 to 16 because I knew I was different, and the stress* caused *me to pull my hair out*".(P203/00:15:43)

Laughing, she recalled her angry reaction to '**being forced to socialise**' CS, when a teacher "*separated me and my best mates. They separated to...to try and get me to socialise with more students… They separated me from my close friends, and that really angered me*".(P203/00:12:11) Her '**social difficulties**' CS, appeared to result in her preferring to be "*with adults than children my own age*",(P203/00:15:34) and often spending her lunch breaks with her "*brother's girlfriend* (who worked at the school)".(P203/00:15:14) Although, Jane did recall "*yeah, I think I had some friends in primary. I don't really remember*".(P203/00:14:58)

ES-CSS (Evidence of good support practice)

Jane's '***brother's adult girlfriend***' provided her with ES-CSS during lunch breaks, as well as a '***reception worker***' (mum's friend). '***Mum***' provided Jane with ES-CSS, but sometimes this was not possible during the infant CTT due to Mum not being made privy to Jane's social difficulties and challenging behaviours, Jane believed that this was because,

> "*Mum was friends with one of the reception workers, and they...I think they had like a bit of like a bias that... there probably was something wrong but they didn't kind of, like, bring it up to my parents because they're like oh, we know* 'Jane' *since she was born. She* (Jane) *… kind of finds it hard to share and she does need a bit of mothering. But...because they know me from such a young age, you can kind of have like a skewed perception*".(P203/0012:42)

4.6.4 Procedural steps 1-2: Primary (junior) CTT

4.6.4.1 The major concurrent stressor 'being undiagnosed ASC' (Un-CS)

Jane continued into junior school with the major CS '**being undiagnosed ASC**'. Jane expressed, in a serious tone, her belief that "*because I didn't have a diagnosis, they all just thought I was a problem child… I was never naughty. I just never knew that that was a thing that wasn't norm*".(P203/00:16:42) This resulted in CS due to '**being labelled as a problem child**'.

Lack of Un-CSS

She attributed her lack of Ac-CSS and ES-CSS as the result of not having a diagnosis ('**being undiagnosed ASC**' CS), "*because I didn't have a diagnosis, obviously, the council didn't have the funding*".(P203/00:17:56)

4.6.4.2 Academic concurrent stressors (Ac-CS)

'**Difficulty with English language**' CS continued from the infant CTT. Mum's perception was that Jane was disadvantaged as an English learner even though she was academically capable, that "*she struggled to put it down, and I think because they word things differently, obviously she gets marked down because she hasn't put it in the context that they want them to*".(PFM203/00:10:25) However, Jane was proud of the fact that she was "*in the top of year in math. I was at the top of the year for science*".(P203/ 00:24:50) Jane stated, with a serious tone, that her Ac-CS was likely to be related to CS due to being, "*severely ... pretty dyslexic... really dyslexic…*",(P203/00:20:21) which was not diagnosed until the end of the secondary CTT aged 15 years. Jane shared Ac-CS, '**falling behind in English**', which she felt was due to lack of Ac-CSS from the school.

> "*I feel like they didn't support me enough … They kind of just thought oh, your rubbish at English you're going to fail English, that … kind of thing*".(P203/00:20:32)

Lack of Ac-CSS

Jane stated that the school did not provide her with Ac-CSS.

4.6.4.3 Emotional-social concurrent stressors (ES-CS)

Jane shared that she experienced severe mental health (MH) difficulties due to a variety of ES-CS, in particular '**anxiety**' which first started in the infant CTT, "*probably age of about six, seven*".(P203/00:17:31) This was followed later by '**anorexia**', which started in the junior CTT. Jane shared this information, looking down and using a quiet voice, "*I know I had anorexia at the age of 10*",(P203/00:17:31) until "*…17*".(P203/00:17:46) Mum believed that Jane's '**anorexia**' was triggered by emotional exhaustion and social pressure from her peers, expressing, "*she* (Jane) *became mentally excited. She went anorexic. They* (her peers) *told her to stop eating. She went that thin it was that unbelievable. She was very clever at hiding it I would say*".(PFM203/00:20:10) Jane also continued to experience ES-CS '**trichotillomania**' and continuation of major '**sensory challenges**'. Jane was emotional as she reasoned why she had poor MH, outlining, "*…the main trigger was social… But also, the lack of support definitely*".(P203/00:18:02)

Jane voiced how ES-CS resulted from '**being bullied**' and '**social difficulties**', that these experiences shaped her concept of self, her perception that others hated her and that something was wrong with her. Based on this perception she disclosed that this resulted in her 'punishing' herself, "*…because ... like, people hated me, and I hated... I didn't know what was wrong with me. I hated myself*". (P203/00:17:40) "*Therefore, that was why I used to punish myself*".(P203/00:17:48) Jane continued to describe, in a sad tone, how the junior CTT was the worst for '**being bullied**', that this bullying resulted in long term damage and that this was the reason she continued to have treatment now.

> "*Yeah, junior school was probably one of the worst for the bullying ... I mean, I'm still having treatment now for the damage that they've done*".(P203/00:15:43)

She claimed that 'back breakers' in the school yard resulted in permanent damage to her spine, "*.. oh yeah that affected my spine … So that's why I sort of got problems with my lower spine*".(P203 int-2/00:08:43) Mum was emotional describing how she requested CSS from the head teacher during this incident, which was not given and that she was told that Jane was the one causing the fights.

> "*That particular girl and her friend … used to get her in the playground and apparently to kick her in her back, do that dropkick on her back quite often, but*

> *when I went in about it the headmaster just said it was Jane that was causing all the fight. She'd watched her apparently*".(PFM203/00:11:34)

To alleviate ES-CS resulting from '**being bullied**', Jane explained that she would, "*never go out on the playground because I'd get, like...every time I went out on the playground, I'd get beaten up*".(P203/00:13:33) On the occasions when she did mix with her peers in the playground, she stated that the degree of '**being bullied**', increased.

> "*…sticks and stones thrown at me. This was in Year 3* (aged 7/8 years). *My best friend came over and just said, 'ignore them' ...So, I just thought oh, it's best for me to stay out of the way. So, I was under this SEN* (special education needs)"(P203/00:13:33)

> "*...lunch times… I spent most of my time in the SEN rooms*".(P203/00:14:34)

Jane shared more ES-CS that occurred for her during this CTT such as, '**feeling like the odd one out**' and '**being forced to socialise**', describing how, "*they tried to do like sewing clubs to make me socialise with people, but I still really struggled with...*(stuttering)*… Cause, I would always be the odd one out*".(P203/00:13:33) Jane's mum sounded sad when she recalled how throughout primary school (infant/junior) Jane wasn't given the opportunity to socialise outside of school, "*unfortunately, she never really got invited to any parties*".(PFM203/00:00:57)

Jane smiled describing her socially inappropriate behaviours.

> "*I used to … have a joke that I'd go around squishing people's bananas… I loved squishing people's fruit*"

In her defence she went on to state that, "*no one told me this was a thing that was wrong*".(P203/00:16:08) Continuing she shared that this behaviour resulted in a '**parent screaming in her face**' CS and telling her to stay away from their daughter and other classmates.

> "*…I had this mother pull me over and scream in my face to keep away from her daughter and other people in the class*".(P203/00:16:08)

Her mum attempted to request CSS from the school to help address this incident but, as Jane explained, "*... the school didn't care*".(P203/00:16:08)

Lack of ES-CSS and '**teacher's negative behaviours towards her**', appeared to shape Jane's perception of other's feelings about her, her belief that some teachers did things to deliberately cause her stress. She gave the example of a teacher in year four (aged 8/9 years) who would, "*…every week… move me to a different seat because she knew it would unnerve me*".(P203/00:18:38) Jane explained that again mum attempted to seek ES-CSS by going into the school and she tried to address the '**teacher's negative behaviours towards her**', but that the school simply blamed this incident on Jane, that this was "*…her problem…*",(P203/00:18:38) and that the teacher was, "*…trying to find somebody who likes her*".(PFM203/00:00:57) It was Mum's belief that, "*the teacher totally disliked Jane so obviously Jane was always in trouble and it was always Janes fault*".(PFM203/00:00:57)

<u>ES-CSS</u> (Evidence of good support practice)

As stated earlier, Jane frequently commented on the lack of ES-CSS given throughout this CTT, Jane specifically stated that the head teacher did not provide her with ES-CSS. However, she mentioned that the '***SEN unit***' did provided ES-CSS during her breaktimes, where she would spend most of her time. Jane also shared how positive ES-CSS started when others provided her with activities to "*get her energy' out…in the multi sports club which was two times a week, about two or three hours in the afternoon*".(P203/00:16:50) These activities appeared to positively help her well-being, as noted in her positive facial expression when talking about this. '***Mum***' continued to be Jane's main ES-CSS.

4.6.5 Procedural steps 1-2: Secondary CTT

4.6.5.1 Emotional-social transitioning concurrent stressors (EST-CS)

Even though Jane was glad about leaving the primary CTT she stated she was sad that her best friend who was going to a different school and '**apprehensive due to the social upheaval**' CS.

> "*I was going to be thrown into a whole social upheaval again*".(P203/00:23:51)

EST-CSS (Evidence of good support practice)

During Jane's transition into secondary school, she was given EST-CSS through the primary and secondary school's '***SEN departments***', with other children who had additional needs. Later removed due to lack of diagnosis (see: No Un-CSS).

> "*I was put under the SEN department. So, I went on a SEN visit with primary to secondary …and that really helped because I met kids that are like me…*"(P203/00:21:11)

4.6.5.2 The major concurrent stressor 'being undiagnosed ASC' (Un-CS)

Jane's secondary CTT saw continuing major '**being undiagnosed ASC**' CS, which resulted in her '**being refused entry into the SEN unit**' CS, when they realised that she wasn't officially diagnosed with autism.

> "*Two weeks into secondary school one of the SEN workers came up to me and said, 'oh you don't have a diagnosis… you're putting it on, you're not allowed in here' … and kicked me out of the SEN centre… and I…and I went back again crying and I went to the mentor crying saying please, let me in*".(P203/00:21:24)

This appeared to cause Jane considerable distress with her going back to the SEN department crying and pleading for their ES-CSS, for them to let her in. However, she was told "*no, we haven't got…we haven't got…we haven't got the money for you, you haven't got a diagnosis and you're not…you're not coming in*".(P203/00:23:15) They told her that she was only eligible to access SEN CSS if diagnosed with autism, and that she would have to purse a private assessment because they didn't believe she was eligible for referral.

> "*I* (mum) *was told if I wanted any diagnosis done, I'd have to pay for it, but they didn't feel she had anything, and I believed later on in life* 'Jane' *said that she was actually taken out of SENCO* (Special Educational Needs Coordinator). *They had no support, but I wasn't aware of this*".(PFM203/00:15:20)

Jane sounded annoyed about still being undiagnosed during this CTT, stating that this was why, "*the first 15 years of my life I really struggled to understand who I was*".(P203/00:01:41)

Un-CSS (Evidence of good support practice)
Although she initially had transitioning support, several weeks into the first term at secondary school this '***SEN***' CSS was withdrawn, when they realised that Jane did not have an official diagnosis, which resulted in her '**being refused entry into the SEN unit**' CS. '***Mum***', as Jane's primary provider of CSS, said she was given very little information about the SEN transitioning support. When Jane was removed from the SEN department her mum was told that if she wanted Jane to have access that she would need to have her assessed and diagnosed, which she would have to do privately and finance herself. The support workers also went on to say that, in their opinion, an assessment wouldn't reveal anything.

4.6.5.3 The major concurrent stressor 'sensory challenges' (SnC-CS)

In secondary school Jane experienced sensory related CS through '**being bullied**' due to her peers realising that she had '**sensory challenges**' (SnC) which they could use to bully her, by regularly clapping and screaming in her ears. She believed this was their attempt to aggravate her, and that this increased her ES-CS.

> "*Yeah and people purposefully made it worse … clapping in my ears, screaming at me…screaming at me…people purposefully aggravated*"(P203/00:39:22)

She continued to say, "*… got kicked out didn't I … I couldn't go to the SEN* (when sound sensitivity occurred), *the place that I always knew my safety. I couldn't get in there*".(P203/00:39:22)

4.6.5.4 Academic concurrent stressors (Ac-CS)

Jane dramatically stated that, "*my secondary school was absolutely rubbish*".(P203/00:24:16) She stated that her Ac-CS, particularly '**difficulties with English language**' continued and resulted in her being, "*put in lower sets*".(P203/00:24:16) She went on to state that this not only applied to the subjects she struggled with but also the subjects that she was good at too, and as a result, "*…my math and my science level dropped*".(P203/00:24:16)

Jane mentioned the positive Ac-CSS, from her '***English teacher***', who removed Jane from other classes to give her extra English lessons. However, this resulted in Ac-CS due to her having '**less geography and history classes**', which she felt was detrimental to these, her favourite subjects.

> "*My teachers really helped me in English, but they would pull me out of these lessons (Geography and History), and it was just a horrible experience*".(P203/00:28:13)

<u>Ac-CSS</u> (Evidence of good support practice)

Overall, Jane described how she felt the lack of Ac-CSS prior to her GCSE, age eleven to fourteen years, resulted in a decline in her academic grades.

> "*In year 8 (aged 12) I was predicted to get 9 A stars and 8 A's due to…and if they had…I had support, I would've got that, but because of lack of support I left with 2 A's, 6 B's and 3 C's*".(P203/00:24:16)

Mum did say that, during her secondary education, some Ac-CSS was given, but she believed that it was not enough.

> "*She* (Jane) *used to have a one-to-one in a library with some support worker, but it was like for half an hour which Jane probably needed a little bit longer. But I don't think they did very much in a way that it helped her*".(PFM203/00:15:20)

Jane happily reflected on the positive Ac-CSS received from '***some of her secondary school teachers***', in particular; her '***music teacher***', '***history teacher***', '***geography teacher***', '***English teacher***'. She explained that she needed Ac-CSS, "*to keep me engaged in things…especially math because I got kicked out of math lessons for two years, so my math really struggled*".(P203/00:25:03) Continuing, that she,

> "*only got good at English because I had the teachers support and I feel that's why I'm good at history and geography today …it's the teachers support through the GCSE; I came to love the subjects…my history teacher, he was brilliant, he was very good at the subject that he taught. He was clearly passionate about it. He always taught in a way that was easy to understand*".(P203/00:34:06)

In the member checking interview, Jane talked about her '***history teacher***' again and went on to describe how, "*he never talked down to us, he always put a lot of energy into his lessons, he never used 'jargon'…*"(P203 int-2/11-51) and was "*always very approachable*".(P203 int-2/12-26)

Jane described other '***teaching techniques teachers used***' that helped her such as "*personification*".(P203/00:27:50) She also mentioned that she liked it when teachers '***represented information visually***'.

> "*My geography teacher used to draw things. Which is where I found I was visual …like visual memory and I drew my GCSE's and she helped me. She liked making stories, … it's like 6-inch-high heels for like the water level … I could remember the facts visually. And I still up to this day draw my…draw my…even at university degree I still draw some...I do obviously put more writing, but I'd still draw some of my things because it helps me remember*".(P203/00:27:02)

Ac-CSS was also provided in the form of '***reasonable adjustments***' for Jane's GCSE exams, "*extra time and … a smaller room*".(P203/00:30:37)

4.6.5.5 Emotional-social concurrent stressors (ES-CS)

To survive the ES-CS of secondary school, continuation of '**being bullied**', Jane explained that she adapted herself, stating "*I got quite violent*".(P203/00:32:26) She described her realisation that she needed to fight to manage her ES-CS.

> "*In primary school I got beaten up and I used to just let them do it. And by secondary school, by year 9/year 10* (aged 13/14 years) *I wasn't taking any shit … I was like, the only way…the only way I could stick up for myself, there's no point talking, I'm just going to have to fight*".(P203/00:38:02)

Jane said in member checking that she attempted to, "…*ignore it…*", however, came to the conclusion that, "*…people that are just like it's literally physical violence that I'm going to have to use to get people to shut up and it did work*".(P203 int-2/00:21:56) Jane was emotional when she shared her means of venting her anger, how she, "…*used to go in the toilets and there's literally still dents in the toilet from when I used to punch and kick the wall*".(P203 int-2/00:25:47) She summed up her experiences at secondary school, stuttering and looking down at the floor, as "…*hell*".(P203/00:31:24)

In the first few weeks of secondary school, Jane recalled how she, "*met friends with SEN* (special educational needs) *and people who are like me*".(P203/00:21:24) However the CS due to '**being refused entry to the SEN unit**' resulted in severe distress for Jane, with her going back to the SEN unit pleading that they let her in, to be told, "*... you need to stop coming in here, you need to learn how to make friends. Because you haven't got any disabilities, you've got to go out there and like stop coming in here*".(P203 int-2/00:14:43) She described '**being refused entry to the SEN unit**' CS and '**being alone**' CS, as "*… a whole, like, social conundrum*",(P203/00:21:48) resulting in increased '**being bullied**' CS during her break times and lessons.

> "*I mean about two months in I had my bag shoved down the toilet in secondary school… at break time…* (bullying continued) *... in class*".(P203/00:24:50)

With an air of hopelessness, Jane describe ES-CS resulting from other '**teacher's negative behaviours towards her**', how some teachers didn't want her in their class. She appeared to believe that these teachers, "*didn't really care*". She described how this influenced her coping strategies at the time, regularly skiving off rather than going to lessons and learning, because "*it was so easy to walk out*".(P203/00:28:41) In a loud, assertive voice, smiling, Jane went on to share that she experienced ES-CS because of '**discrimination against her family by her teachers**'. Recalling that she remembered a teacher saying, "…'*you're related to* 'surname' *family, aren't you?*'*… She goes,* '*you're all trouble you lot, aren't you?*'*…* "(P203/00:33:29) In member checking she continued to explain that this discrimination occurred frequently, teacher's prejudices about her family, excitedly elaborating on this topic, with the example of a teacher who, "*…when she found out like from parents evening that I was related to the* '*Browns*'*, she just completely turned on me, she was like you're all from the same brush, there's no point like dealing with you guys and stuff*".(P203 int-2/00:23:24)

On a regular basis during lessons Jane expressed '**confusion at being put into exclusion (isolation)**' CS, which appeared to become a normal occurrence for her. She angrily described how she felt some teachers did this on purpose to 'rile' her, and to provide them with the evidence they needed to support sending her to another school.

> "*Yeah, they put me in exclusion because they knew that it would rile me… so, then they have more excuse to like send me to different school*".(P203 int-2/00:16:14)

Mum was emotional when she shared her concerns about a math teacher who didn't seem to like Jane, how they frequently put her into isolation, where "…*she had to do the work there by herself. That started to happen quite a lot*".(PFM203/00:16:38)

Jane was particularly frank and honest about ES-CS resulting from '**difficulties with social relationships with girls**', demonstrating a preference to hang out with boys instead.

> "…*girls would just constantly bitch about me. I could hear them saying stuff, and I remember once in English someone was bitching about me and I just stood up, threw a pen, and said,* '*if you fucking say that again say it to my fucking face*'*, and then walked out of the lesson… I always associated myself with boys*".(P203/00:32:59)

Jane demonstrated ES strengths, that appeared to help her to manage some of her ES-CS. She described with an upbeat tone, "*I kind of like made friends with the boys… I mean I did adapt myself, you know, at break times I did kind of have a routine of I'd* *stay with the boys and mess around and things like that…*”.(P203/00:22:25) Jane happily described that she, “*became very good friends with my form teacher at the time and she* (the form teacher) *used to do debate clubs, so I used to go down twice a week*”.(P203/00:22:05) She also began a long-term friendship with, “ ‘R’, *who's also autistic and very similar to me … me and him are still really close, because he could relate to what I was feeling*”.(P203/00:32:52)

Mum emphasised Jane's social vulnerability, how Jane hung out with a small group of peers who she believed encouraged her into negative behaviours.

> “*Yes. Unfortunately, what happened with Jane at senior school, she got in with a group of four or five people that realised that she wasn't quite like themselves and encouraged her to self-harm, to try and get her to leave home, to go into foster care, all sorts of things*”.(PFM203/00:08:18)

The Ac-CS and ES-CS, that Jane had to adapt to, resulted in severe ‘**emotional mental health**’ CS, which Jane appeared to negatively attempt to manage through multiple ‘**self-harming**’ episodes and two ‘**suicide attempts**’ by the age of 13 years, as well as continuing ‘**anxiety**’ CS, ‘**anorexia**’ CS and ‘**trichotillomania**’ CS.

> “*…When I was at school, I was having them* (incidents where she was self-harming) *every week*”.(P203/00:57:46)

> “*I had two suicide attempts by the age of 13*”.(P203 int-2/00:23:58)

Prior to doing her GCSE exams, aged 15 years, Jane seriously ‘**self-harmed**’, in what she described as an ‘attempt to commit suicide’.

> “*I … cut myself and tried to infect the wounds*”.(P203/00:36:02)

This resulted in her being admitted to hospital and having to leave school. Mum, timidly and emotionally, shared her memories of Jane's serious ‘**self-harming**’ incident, highlighting how initially the incident was put down to behaviour and anxiety, which was treated with anxiety medication. She continued, that it took another six months before Jane's ‘***mental health***’ CSS team decided to refer her for an autism assessment.

> "… *They* (Child and Adolescent Mental Health Services: CAMHS) *put her on medication, still didn't send off any sort of diagnosis for quite some time, six to seven months we go to see a psychiatrist and then eventually he said*, '*It's not psychological. We're going to have her assessed*' *...*".(PFM/00:06:46).

Jane rationalized that her suicidal attempt was based on her perception of other people's thoughts towards her.

> "*…because it was like people want me dead anyway. The last time I tried to kill myself no one tried to save me, so it was like so they obviously want me dead now so I might as well go quietly kind of thing*".(P203/00:36:34)

She also mentioned that it was '***a friend***' who alerted others to her plight, that she, "*noticed all the skin on the tights and went and told the teachers and then obviously they asked to see it… And I was rushed to hospital*".(P203/00:36:43)

ES-CSS (Evidence of good support practice)

Jane appeared to receive ES-CSS from '***a friend***' who told her teacher about her infected wound, and from '***male peers***' she hung out with, as well as continued support from '***mum***'.

Mum outlined the ES-CSS Jane received outside of school at that time, from '***NHS's Child and Adolescent Mental health Services (CAMHS)***', "*she went to this psychiatrist … nearly every week or every fortnight for quite some time then she saw … her nurse for ... CBT ...she said I can't do anything with her*".(PFM203/00:23:08) She went on to say, that Jane had started to become confused about reality and imagination.

> "*…she would say things that… we now say to her*, '*Is it what you think is really happening or did it really happen?*' *... because she was saying things that she in her head thought that was happening … but that actually wasn't happening. So, they would obviously listen to what she was saying and then we'd have to go and say.* '*No, it wasn't this, this, this, and this*' *...*".(PFM203/00:23:08)

Jane also sounded disappointed when she described the support she received and the mental health nurse who worked with her.

Jane expressed that no additional ES-CSS was put in place for her when she returned to school after being in the hospital.

> "*I just feel like it was never resolved. I feel there was never enough help to resolve it. I went back to school and it was still the same shit*".(P203/00:37:20)

Following Jane's diagnoses, mum was told by the secondary school that Jane was no longer allowed to attend, "… *they* (the secondary school) *wouldn't have her in school. They said she was a liability*".(PFM203/00:24:22) Although, when it came to Jane's GCSEs, Mum said, "*she actually did the exams at school*".(PFM203/00:24:32) Jane, talked about being pleased to not be returning to school. She said she felt, "*really happy*" to be "*getting away from…getting away from that place… academic, social, teachers*". However, she continued to say that she felt anxious and scared that the experience of 'being bullied' in secondary school, would continue in sixth form, "*Being bullied* (in sixth form) ... *bullied. Yeah*".(P203/00:23:03)

4.6.6 Procedural steps 1-2: Sixth form CTT

4.6.6.1 Emotional-social transitioning concurrent stressors (EST-CS)

Jane factually described ES-CS, that she '**struggled to readapt to sixth form college**', following her autism diagnosis, due to continuing '**emotional-mental health**', Ac-CS and continuing '**social difficulties**' CS. How it took her, "*… about a year or two* (to adapt to sixth form)*, so I had to drop out of college, to like to readapt myself… for the people around me to learn how to support me better*".(P203/00:03:48)

EST-CSS (Evidence of good support practice)

Jane declared that her secondary school did "*nothing*"... (P203/00:40:33) to support her transition into sixth form. Prior to starting sixth form Jane attended an autism only day which was provided by '***autism trained sixth form staff***'. Jane excitedly described that she was offered EST-CSS in the form of "*... an autism only day…*"(P203/00:40:42) which, was now accessible to her "*…because I was diagnosed by that point*".(P203/00:41:45) Jane went on to explain what took place during this '***autism only day***'.

> "*… I met all my lectures … they had day for the year 12*'*s starting where people with learning difficulties went and you did all your lessons… they had a 1 to 1 if you were on the spectrum, they showed us around the college because the college was quite a big place*".(P203/00:41:45)

4.6.6.2 The major concurrent stressor 'sensory challenges' (SnC-CS)

Jane continued to struggle with SnC-CS relating to '**sensory challenges**', recalling,

> "*I was stuck at the back and I was crying, and the teacher made everyone part ways and came and got me and got me out of the class… Yeah. She could see that I was really struggling, she said like everyone come and move the tables...and let Jane through*".(P203/00:59:59)

SnC-CSS (Evidence of good support practice)

It appeared as though ‘***autism trained sixth form staff***’ SnC-CSS was more accommodating of Jane’s ‘**sensory challenges**’ CS.

> “*The teachers would let me go out of the class and they would talk to me individually about what the task was, and they’d let me use a laptop so I could still listen, but from a different room*”.(P203/00:59:12)

She described how in class she could, “*…sit at the front … So, I’d always sit at the bottom by the door and on the end where I could always come in and out if it got too much or the room was too echoey*”.(P203/00:59:28)

4.6.6.3 Academic concurrent stressors (Ac-CS)

Jane shared her Ac-CS during this CTT due to the ‘**academic jump from GCSE to A-level**’, how this was the biggest academic jump that she experienced throughout her education journey, that “*the jump from A-level to a degree is a lot smaller than the jump from GCSE to A-level*”.(P203/01:17:23) She commented that she really struggled, that the “*first six months* (were) *really shit. I hadn’t been in an academic lesson for…I hadn’t been in the academic setting for two years*”.(P203/00:42:32)

Mum explained Jane’s decision to temporarily leave sixth form during her first year,

> “*… she was nearly towards the end of the first year and they just suggested she came out of college for the rest of the summer and then start her year again which she did do, and she found that very useful because ...she knew the college, she knew the lecturers*”.(PFM203/00:25:44)

When Jane returned to college, she ended up doing three A-levels, “*geography, history politics and English literature*”, continuing to state that she, “*had a problem with an English teacher and then…and that was before I restarted and then when I restarted in year 12 … I did geography, history, politics*”(P203/00:43:38) ‘**Historiography**’ CS appeared to challenge Jane the most, as she “*really, really struggled with Historiography … I knew in Historiography I was going to get a U*”.(P203/00:46:40)

Ac-CSS (Evidence of good support practice)

Prior to temporarily leaving sixth form Jane expressed that her Ac-CSS (and ES-CSS) needs were greater during this time and that she initially did not have the support she needed because it needed to be, "… *so much more* …" (P203/01:17:23), than she was getting.

When Jane returned she stated that '***supportive teachers***' provided her with a range of Ac-CSS such as '***positive communication***', '***personalized (individualized) teaching***', '***reasonable adjustments***', by making '***additional efforts***', and by '***adapting their communication style***'. Jane described how she benefitted from a teacher who '***adapted their communication style***', such as giving her choices and by not being confrontational with her.

> *"Yeah. Like instead of going "Get out!" it's like "You either be quiet or you can remove yourself from the room".*(P203 int-2/00:30:07)

The sixth form '***reasonable adjustments***' put in place for Jane were '***extra time***', '***a smaller room for exams***' and '***toilet breaks***', as well as '***support with exam anxiety***' (during A-level exams).

> "*If I got panicky before the exam, I'd always go to the teacher's staff room and I would walk out with a cup of tea. If I was really stressing the teachers would walk me down to the exams with me*".(P203/00:51:27)

Jane gratefully recalled the significant Ac-CSS that she received from her '***history teacher***' who '***personalized (individualized) teaching***' to suit her learning style and how this teacher allowed her to stay with her friends in class.

> "*This one teacher, bless her, oh she was a gem yeah, she was amazing because I was going through family financial problems and they helped me with that. She bought me a book on how to do Historiography and every morning from 8:30 to 9:30 up to my year 13* (aged 17/18 years) *exams she sat down with me and taught me how to do sources. And luckily because of her I got a C on my source paper… I was predicted a U; I got a C just because she put in all that time and effort*".(P203/00:46:40)

> "*My history teacher knew that I always worked best in class by sitting on the floor. And she just let me sit on the floor … She was like sit…sit on the floor, sit on the desk, sit on the table, whatever you want. She was really chilled, and she kept me with my friends. …and oh my gosh just…I just can't explain how helpful that was*".(P203/00:44:26)

Mum was upbeat reflecting on Jane's academic strengths in sixth form, with particular gratitude towards the Ac-CSS given by her '***geography teacher***' and '***politics teacher***', sharing that "*… the geography teacher understood her and taught her in a way that Jane could interact. Now, that politics teacher was fantastic, absolutely fantastic. … She excelled in politics. She loved it*".(PFM203/00:27:26)

Jane sounded grateful when she talked about how the sixth form provided Ac-CSS '***during trips abroad***'.

> "*I went to, like, Belgium … I've had experiences as well; I mean I went abroad with them… I went to New York… I went to France with the Geography*".(P203/00:46:49)

She appeared thankful for the '***personalized (individualized) teaching***' CSS that she received at this time, how her teacher would, "*explain everything*" to her, highlighting that she was given choices, and independence, during these trips, to go "*…around by myself*".(P203/00:46:55)

Jane proclaimed that her sixth form Ac-CSS, "*… allowed* 'her' *to thrive…*" (P203/00:45:12) and that they, "*…allowed like my intelligence to come through*".(P203 int-2/00:29:58) She sounded proud revealing a boost to her 'self' when, prior to leaving sixth form, she was voted "*a student ambassador …student for the future… they* (people who voted) *think I am gonna to do something well in life*".(P203/00:09:01) As a result of this award Jane regularly returns to her sixth form to do autism talks, to inform others about support in education. She also helps to train student doctors about potential autistic patients.

Finally, Jane shared that she did exceptionally well in her A-Level exams, gaining results that were higher than her predicted grades (given to her in year 12) and that she obtained one of the top Geography marks in the UK during this academic year.

> "*So, when…I was predicted three C's at the start of year 12. By the time I left in year 13 I got an A and 2 B's*".(P203/00:45:04)
>
> "*I was one of…I was one of the 63 people in the country to get top marks in geography*".(P203/00:44:26) She expressed, "*I really do miss it* (sixth form)".(P203/01:00:51)

Beaming, she depicted how, "*the teachers were there to put in their time and effort*".(P203/00:46:44) They "*…individualised … learning…*"(P203/00:50:19) as well as "*… one to one personal support that really, really helped*".(P1/00:47:32)

4.6.6.4 Emotional-social concurrent stressors (ES-CS)

Upon Jane's return to sixth form college, she stated that at first she had ES-CS because she '**struggled with her autism diagnosis in general**', that she did, "*struggle at first…*". Although she did not appear to fully understand why, "*I don't know why, I just did*",(P203/00:03:36) she recognised this was likely to be due to her '**emotional-mental health**' CS at this time.

> "*I mean, that's probably cause I was still in the stage with mental health things*".(P203/00:03:56)

When asked how she felt about her autism diagnosis, it was clear that '**being undiagnosed ASC**' CS, had caused Jane considerable ES-CS and that this appeared to dissipate once she received her diagnoses during this CTT.

> "*...It is...it* (being diagnosed) *kind of made sense that living 15 years of my life wondering why I was so different; I knew the reason… I spent 15 years in my life not knowing the reason why I was like the way I was*".(P203/00:03:06)

How being diagnosed, "*was kind of like a big weight*",(P203/00:03:29) off her shoulders. Jane gave an emotional illustration of how her mum had "*cried...because she* (mum) *knew through 15 years of my life that...there was not something was wrong with me, but she* (mum) *knew that... I was different*".(P203/00:03:27) Although, Jane shared that she experienced ES-CS due to '**others stereotypical views of autism**', when they made dismissive statements to her, or in front of her, such as, "*oh,* '*they*'*re autistic*'*... and I found that hard as well because there was a stigma around it*".(P203/00:04:05)

Jane smiled as she shared that during her sixth form years she continued to have '**social difficulties**' CS, experiencing '**social exhaustion**' CS, particularly during field work and school trips. She expressed frustration missing "… *out a year of my education because of the way I was treated*",(P203/00:38:48) resulting in '**reminiscing about the way she had been treated previously in school**' CS. Going to sixth form college and, being treated 'properly' resulted in Jane having an emotional realisation that she had been treated badly by people in the past, and that the way she had been treated in the previous CTT wasn't normal or acceptable.

> "*…when I got into college and I was actually getting treated properly, I was like no, this is like how I*'*ve been treated all my life. That*'*s like when it clicked, I think that*'*s when it kind of snapped, I was like yeah, the way I*'*ve been treated isn*'*t very good is it*".(P203 int-2/00:27:48)

She described her '**emotional mental health**' CS, during sixth form, as "… *still up and down. I was still struggling with it…*". but, she continued to say, "*…it was a lot better*".(P203/00:57:32) She talked about a marked reduction in her '**self-harming**' episodes.

> "*…it* (self-harming) *was a lot more stable. I did have like one or two self-harming incidents whereas when I was at school, I was having them every week*".(P203/00:57:46)

Jane's '**anorexia**' CS continued until the end of the first year of this CTT and '**anxiety**' CS remained ongoing. Jane, sadly disclosed, the '**self-harming**' CS triggers at college were, '**stress**' CS and '**people bitching and talking behind her back**' CS.

> "(Self-harming triggers) *Stress, people bitching, but mainly stress… What people think about me. … I get worried about what people think about me, but it was just that like I hate people talking about me behind my back because I*'*m a very forward person, like, if you have a problem come and talk to me personally about it*".(P203/00:58:43)

ES-CSS (Evidence of good support practice)

Jane was proud and grateful for the ‘***autism centre***’ ES-CSS provided by the ‘***autism trained sixth form staff***’, how “*… the one’s in sixth form make sure that every single teaching day that it is… they have to do something to do with autism … Everyone had the choice to be trained and a lot of people did choose*”.(P203/00:48:16) In particular, she praised her ‘***mentor***’ (specialised support worker), and the support she received from the ‘***Head of the autism service***’.

Jane shared the relief and happiness that she felt when, finally, ES-CSS took the form of others telling her that her behaviours were “*…normal, and that it’s fine, and there’s a reason why people behave the way that they do*”.(P203/00:03:11) Mum shared how Jane’s diagnoses resulted in better ES-CSS because, she was now “*... more understood*”, how upon her return to retake her first year she started “*…calming down ...*” and, that she now knew who to go to for CSS, “*... and realising that she could go and get support ... she knew she could go to somebody that could help her put things into perspective she coped a lot better*”.(PFM203/00:32:30)

Mum disappointedly shared how ES-CSS from family was limited at this time, how, “*it took a very, very long time for her dad. He would not accept that Jane has got autism*”.(PFM203/00:30:37) Mum also described how one family member, “*just kept saying she was mad basically*”(PFM203/00:30:46) and, that she felt “*her* (Jane’s) *older brother and sister ... I don’t think they really understood it* (Jane’s autism) *either*”.(PFM203/00:31:07).

Prior to her returning to college, Jane received sixth form ES-CSS. ‘***She went into college one day a week***’ when they taught her, “*... how to get back into a classroom environment and then towards my anger management and stuff*”.(P203/00:38:23) Jane factually outlined how, upon her return to sixth form, she was ‘***taught appropriate behaviour and communication skills***’ for the sixth form environment, as well as ‘***taught techniques that would enable her to learn in class***’.

> “*I would come back in every like two or three weeks and they’ll teach me how to behave and teach me what’s appropriate and what’s…stuff that I’d never been taught from a young age… They just like showed how to take notes in class and … you shouldn’t shout out and stuff and this and this and this and that*”.(P203/00:44:00)

When Jane started this CTT the '***autism centre***', in the sixth form college, provided her with '***mentor***' CSS, "*… in the mainstream classes… but I had a mentor that sat in my classes with me … Yeah, like a teaching assistant*".(P203/00:42:06) When she restarted, she decided to not continue with her '***mentor***' in lessons, wanting to be more independent in lessons, although she did continue to have '***mentor***' ES-CSS outside of lessons.

> "*…I decided that I learned enough that I would just rather go with my lessons and be myself*".(P203/00:54:21)

She stated that she felt '***supportive teachers***' provided positive '***personalized (individualized) teaching***' CSS, giving the example of , "*field work, a lot of the times like I'd get socially excited…because the classroom was really small at this fieldwork centre, they let me go in my own room a lot and they let me sleep and stuff as well*".(P203/00:50:01)

Jane shared another example of how this '***history teacher***' provided her with ES-CSS, when Jane got, "*…really angry and …* 'she' (Jane) *screwed up* 'her' *coursework paper and threw it in the bin*". Continuing, how this teacher's supported her by getting her "*course work out* (of the bin) *and re-typed it*", and then telling Jane "*we're gonna do this together*".(P203/00:50:29) Jane proudly stated that she "*… got an A in that coursework*".(P203/00:50:29)

Once settled into sixth form it appeared as though Jane received ES-CSS from '***friends in*** '***creature corner***'' and found a safe space to hang out with them. Excitedly describing herself as having 'loads' of friends who gave her ES-CSS due to having autism themselves and/or understanding autism. Continuing that, even though she, "*did struggle with…socially in college. Like people still bitched about me and stuff… I didn't care because I had my own group of friends…* (who hung out in a place) *called creature corner. It's where all of the weird kids would go*".(P203/00:55:15)

When '**self-harming**' CS occurred during this CTT, in contrast to previous CTT where the teachers couldn't cope with it, the sixth form provided ES-CSS which she found helpful. This was usually through her '***head of the autism service***' whom she would go to for support, "*…she'd really help*".(P203/00:57:57)

Emotional-mental health specific CSS, Jane happily described, as being provided through access to '***the cupboard***'. This was a safe place she could go when she experienced '**having a meltdown**'. She described what tended to happen when she had an episode, "*the thrashing ones* (meltdowns) *where I just scream, and I thrash*". She continued by describing an incident where the teachers had to intervene and how they "*…managed to restrain me properly and treated me all right, and told me everything was okay, and .... and like...and like held me, and like ... and that support, I had...I had never gotten it in education before*".(P203/00:07:29) Jane was shocked and grateful for the '***supportive teachers***' and '***head of the autism service***' ES-CSS at this time. When she returned to college a few days after an incident, she said that they had cleared up the mess that she had made. Jane appeared shocked that they did not punish her and, instead, treated her as if nothing had happened.

> "*They cleaned all my mess up! ... and they were so understanding ... and I came back a few days later, and they were completely quiet about it, like it never happened… I literally wrecked. I pulled books off the shelf and everything, and they didn't...they didn't penalize me for it*".(P203/00:07:47)

She emphasised the positive influence that '***the cupboard***', her place of safety, had on her.

> "*When I was struggling to concentrate or if I was, like, laughing or distracting others then I didn't realise, and they were like would you like to remove yourself to the cupboard… like, a separate room there. If I was struggling in class, if I was being too disruptive or if I couldn't concentrate, I could go into the cupboard… it was a nice space it was roomy; it was airy…I had like an access card to get in there... I could revise in there, and it meant I wouldn't distract people, people wouldn't distract me*".(P203/00:06:52)

4.6.7 Procedural steps 1-2: University CTT

4.6.7.1 *Emotional-social transitioning concurrent stressors (EST-CS)*

A large smile appeared on Jane’s face as she described when she first made the decision to go to university and, the influence that others had on this decision when they told her she was intellectually capable to go.

> “*I always wanted to learn more. I’m one of those people who actually ask...I’m like a 2-year-old but I keep asking questions... I was always told to go to university...to apply*”.(P203/01:02:38)

She was most excited about picking her “*own research…I loved...that’s why I knew I’d do honours …So, I can pick my modules… what I’m interested in*”.(P203/01:03:32)

Jane was proud of the fact that she has autism, she articulated that disclosing her condition was not a stressor for her. Expressing her passion about society adapting to the ‘disabled’ individual rather than the other way around.

> “*I chose to disclose because of like...well, you have to disclose if you need support...I’m not ashamed of it. I’m not ashamed to be autistic. A lot of people have this shame that goes along. I don’t care. I’m not ashamed. It’s not a phase, it’s who I am*”.(P203/01:22:02)

> “*Instead of us trying to adapt to society, which is impossible, pretty much, society’s just gonna have to find...adapt to us*”.(P203/01:22:17)

EST-CSS (Evidence of good support practice)

During the transition into university Jane was provided with EST-CSS by her ‘***parents***’.

> “*Yeah, yeah, they* (my parents) *took me to open days and my mum corresponded with the autism services … they gave me as much support as they can, and in fact, and they still give me support*”.(P203/01:11:59)

The ‘***sixth form***’ also provided Jane with EST-CSS transitioning, which she described as a positive experience, ‘***helping her to identify universities support services***’ and ‘***telling her about the specific support services that her*** ‘***chosen***’ ***university provided***’.

> “*Yeah, yeah, I mean my support from my college...my personal experience. From sixth form to university was very, very positive… invited people from the university to come in and teach people... they gave out a booklet…like a moving on up booklet*”.(P203/01:24:58)

They appeared to ‘***help her to understand how the university worked***’, ‘***what to expect in lectures***’ and ‘***how to prepare for the research elements of a degree***’.

> “*… after exams we kind of went back into college and they taught us how our lectures and stuff worked… how university worked... they made sure that in year 13* (aged 19 years) *that the teaching style was very similar to university… and like taught me how to do research and stuff*”. (P203/01:03:13)

The sixth form ‘***informed Jane about her entitlement to funding for additional university support***’, which was available to her via ‘***Disabled Student Allowance (DSA)***’ and they ‘***helped her to complete all the necessary forms to access this at university***’.

> “*Yeah. That was from...that was from college. College did DSA and everything like that*”.(P203/01:13:09)

The university provided Jane with EST-CSS through ‘***Skype calls***’ with her, which she stated, “*really helped*”. Jane continued by sharing what a positive difference it made knowing that she, “*was coming into a place that ... would now have continuing autism support*”.(P203/ 01:01:38) Jane declared the EST-CSS that the university provided, in the form of ‘***a two-day induction programme***’, was extremely useful. She went on to describe what it involved and how it taught her what it was going to be like to be living away from home, as well as the support available. She seemed to be grateful for the opportunity to meet fellow students-to-be, to make friends prior to starting university, and went on to explain how these individuals became her lifelong friends.

> "*Two-day orientation was probably the best...one of the best things they* (the university) *did…* (they told her about the) *support and … all the different services and societies and then obviously* (during this orientation event she met) *people … it meant that I could make friends before I went to uni…* (Jane) *met lifelong friends*".(P203/01:02:09)

Jane shared that she received '***autism specific***' CSS when she arrived at university from the '***ASC service***'.

> "*The autism service was really, really helpful because we could always pop down to you in the first couple of weeks saying I need help...need help and obviously with freshers fest, I think you've got the whole two weeks with you not learning… being able the access support I think was very, very, helpful in settling in*".(P203/01:05:11)

4.6.7.2 The major concurrent stressor 'sensory challenges' (SnC-CS)

Jane shared that she continued to suffer with SnC-CS due to '**sensory challenges**', especially when she was clubbing at university but, that she had learnt coping strategies to manage noise and lights.

> "*I now know if I'm going to go out clubbing in the unknown... the steps I've got to do, I've got to get really drunk before I go out….to stop… the noise …*(which) *triggered me, and the light …*(which) *triggered me. So, I know...I know I can't go out unless I'm, ridiculously drunk*".(P203/01:05:42)

SnC-CSS (Evidence of good support practice)

During the first year of university Jane received SnC-CSS through the '***health and wellbeing department***', she described how they did a hearing test and made her bespoke ear plugs. She appeared overjoyed discovering that she had a unique hearing ability and shared, "*I hear… 23, 24000 hertz whereas an average human hearing, you got 16000 hertz*". (P203 Int-2/00:51:08) Jane went on to proudly describe her greatest sensory achievement at university, how she learnt to manage sounds during lectures and communicate her difficulties to the lecturer when needed.

> "*…I have learnt that if you go closer to the wall you have less reflection…So, I sit in the front close to walls... And also, when the lecturers want to use microphones, I ask them politely if the lecture is small enough if everyone can move to the front because I don't like the echoing from the microphones*".(P203/01:29)

4.6.7.3 Academic concurrent stressors (Ac-CS)

The academic jump from A-Level to degree didn't appear to cause Jane Ac-CS, with her explaining that the academic jump from GCSE to A-Levels was far worse. Jane revealed that there were elements of her degree that she struggled with such as '**doing historical analysis**' CS and '**lacking the foundations of math**' CS, both of which negatively impacted her ability to do the mathematical elements of her university degree.

Mum's tone reflected her concern about Jane's '**struggle with academic deadlines**' CS, and '**not being able to demonstrate her knowledge and academic abilities in written exams**' CS.

> "*Putting things down on paper in the format that the person that's marking that work expects. When they've got it in their head, but they can't put it down on the way… they put it in a totally different context down on paper and that's where they get marked down*".(PFM203/00:47:46).

When asked what her greatest academic achievement was at university, so far, she proudly revealed, "*I've got firsts and 2:1's, I'm constantly getting 2:1's. I think I've* *only ever got one that was a 2:2*”.(P203/01:26:58) Mum shared how proud she was of Jane’s academic strengths, her perseverance, her love of learning, and her passion fighting for the rights of individuals (with autism) in education.

> “*Now at uni she just perseveres, and she just so loves what she does. Like learning, she just absolutely loves it. She loves doing her geography. I think she’s just done brilliant… if she thinks something isn’t right, she’ll tell you … she is fighting for autism people … trying to make people aware that they can’t be treated unfairly*”.(PFM203/00:51:00)

Ac-CSS (Evidence of good support practice)
Clapping with excitement Jane articulated that her ‘***academic department***’ provided her with Ac-CSS by giving her ‘***the opportunity to focus on her academic strengths***’.

> “*…I can focus now on 20th century history. Whereas before I couldn’t…* (geography) *models that have history in them as well. You can sort of chop and change, and I can feel that’s very, very… rewarding*”. (P203/01:20:56)

‘***Disabled student allowance (DSA)***’ CSS provided additional Ac-CSS and ES-CSS in the form of ‘***a notetaker***’, ‘***IT provisions***’, a ‘***specialist autism mentor***’, and a ‘***specialist study skills tutor***’.

> “*I have* (through DSA) *… a computer with Dragon software and stuff on which is really...and Mac Inspiration which is the...MindView… I… have a one-to-one mentor and the one-to-one study skills mentor has helped me so much because it keeps me on track … And helps me set out and plan things*”.(P203/01:13:55)

In order to help with the difficulties Jane experienced with deadlines and expressing her knowledge, the university provided Ac-CSS through ‘***reasonable adjustment***’ such as ‘***extensions to deadlines***’, ‘***alternative assessment***’, ‘***additional time in exams***’ and ‘***rest breaks***’. Ac-CSS, in the form of ‘***extension to deadlines***’, helped Jane to overcome her ‘**historical analysis**’ and ‘**lacking foundations of math**’ CS.

4.6.7.4 Emotional-social concurrent stressors (ES-CS)

The first week of university Jane described as "*…terrifying, but really exciting*".(P203/01:04:38) Jane experienced ES-CS due to '**fear of change**', which appeared to be emotionally-socially scary for her.

> "*Change scared me like being away from home...and having to live by myself and the independence… It was mainly social. I'm very socially wary and social change scared me the most…. I was living with people that I didn't know*".(P203/01:04:23)

Jane expressed her ES-CS starting university as, '**meeting new people**' and '**trying not to be too weird**'.

> "*Meeting new people… Trying to be yourself...not being too weird*".(P203/01:04:43)

'Freshers week' resulted in Jane '**having a meltdown**'.

> "*… the one time I did go I ended up having a meltdown…*(laughs)*… I ended up in the St. John's ambulance…what I can remember is that I collapsed onto the floor and then after that I just don't remember anything*".(P203/01:05:53)

She stated that it took more than one semester before she felt settled at university.

> "*I only settled into uni by the second semester…which is very quick for me. I mean I had my problems with social things*".(P203/01:03:47)

During her first year in university, she lived on campus in student accommodation, with '***Mum***' regularly provided ES-CSS, visiting her, bringing her supplies, and often staying overnight. At this time, Jane experienced '**living in university accommodation**' CS due to living with others who she felt didn't understand her disability.

> "(living with) *people* (in university accommodation) *that don't understand. If people in the flat understood autism, then yeah it would be a lot better, but it's quite hard being with the disabled and going with people that are...that don't understand your disability*".(P203/01:15:36)

However, living independently for the first time didn't appear to be a practical challenge for Jane, who stated proudly that she was used to being home alone, that she had gained skills from scouts and guides, and was able to cook for herself from a very young age.

Mum shared information about an '**argument with flatmates during first term**' CS experienced by Jane.

> "*She* (Jane) …*was hiding under a bush in the Uni grounds absolutely hysterical. She'd had an argument with one of the students on her floor and she basically said she's been kicked out. Obviously, at this end when we're two and a half hours away I didn't know what to do so I phoned security up… Thankfully, the guy who was on duty had a relative who has got autism and knew exactly how to deal with Jane*".(PFM203/00:39:18)

Mum continued to say that he (the security guard) was "*absolutely fantastic with her*".(PFM203/00:39:18)

Jane expressed timidly her biggest ES-CS at university was '**social difficulties**'.

> "*…new people…only because I'm very forward I don't like bitchy people*", and that "*...some of the people I lived with in my flat were quite bitchy*".(P203/01:18:03)

She shared that some of her peers had a "*lack of understanding*", about her difficulties and that she "*really struggled with this*".(P203/01:18:20) She qualified this by giving an example of when she had a meltdown, that "*all of the girls told my now boyfriend that...that I was just attention-seeking and putting it on*".(P203/01:18:08).

Mum felt that Jane experienced '**loneliness**' CS, during her first year due to being left out by her peers, how "…*they used to go off in their own room and leave it her out and she used to quite often phone us and say she was lonely that she was on her own and say she used to take herself up to the library*".(PFM203/00:40:37) Mum described with concern Jane's '**social vulnerability**' CS, during her first year at university, how "…*one night she got drunk, and they left her in a nightclub on her own*". Mum continued to say that toward the end of Jane's first year that this changed when she joined the '***Eureka***' (autism social group), "…*that she finds very, very supportive*…", how this was "…*somewhere where she can go where she said she's treated normally*".(PFM203/00:41:28)

At the time of the interview Jane was in her second undergraduate year. She was living in a house "*…with six autistic people*".(P202/01:15:09) She stated that she now felt "*…like* (she) *fit in more*".(P203/01:15:13)· During the interview Mum expressed ongoing concern about Jane's '**emotional mental health**' at university. How, "*she gets very excited. She finds she can't get out of bed. She doesn't get out of bed here unless we really go on at her to do so. She seems tired all the time, mentally drained… gets herself into such an anxious state*".(PFM203/00:49:43) Although Mum shared her feelings that "*emotionally, she's not as bad as what she used to be. We have the odd moments where we get the call … we don't get the phone calls as often. But once you've put things into perspective for her, she deals with it…*"(PFM203/00:53:13)

Jane proudly shared her greatest emotional achievement so far at university as, being "*self-harm free for, like, a year-and-a-half now*".(P203/01:28:16) Stating that one of the positive contributing ES-CSS factors in this achievement was the fact that "*I know I'm not forced to come here. It's my learning…I feel that…that choice is very, very, very, very important for people*".(P203/01:28:41) However, she continued that she still experienced '**emotional mental health**' CS, having, "*ups and downs*".(P203/01:28:25) Jane felt that her greatest achievement socially at university was having a relationship, sharing that, "*I never thought I'd have a boyfriend… he was probably one of the best things that's happened at university*".(P203/01:27:12)

Jane excitedly shared her boyfriend's initial perception about individuals with 'mental health issues', how "*he was one of them boys that said, I'd never go out with someone with mental health issues, I could never*".(P203/00:09:41) How he stated that he, "*could never deal with it, and even when we were friends it's like, I'm never taking you out at night because I couldn't deal with you… Because he had seen me having a meltdown*".(P203/00:09:57)· However, Jane outlined how he changed his mind, seeking information from well-being, "*…before I got with him, he...I think he'd...he came down to a well-being… and asked for, like, pamphlets and stuff. And he educated himself*".(P203/00:10:01) Jane explained how she uses the above example about her boyfriend to demonstrate that strong opinions can be changed, that "*people can have such staunch opinions, but if they have a little bit of research and knowledge and they get to know the person that they...it can completely change them*".(P203/01:11:06) She continued by expressing that her boyfriend is now ‘*good with her*’, that he wouldn’t want her to take a cure if there was one.

> “*... he’s so good with me now. But even he said...he’s like, I love you so much for who you are. He’s like, if they ever...if you ever want to take a cure, he said, I will snatch it out of your hand anyway*”.(P203/00:10:01)

ES-CSS (Evidence of good support practice)
‘***Mum***’ continued to provide ES-CSS through ‘***regularly visiting***’ Jane, ‘***bringing supplies***’, and ‘***staying overnight***’.

‘***Eureka peers***’ (autism social group) provided Jane with ES-CSS through ‘***positive friendships***’. Jane expressed her joy attending ‘Eureka’, stating that the ES-CSS it provided “*… helped me a lot, a lot of my housemates are from Eureka… there’s a lot of people to choose from*”.(P203/01:21:32) Positive ES-CSS also appeared to come from a ‘***friend from home***’ who was at the same university which she shared, “*… really helped ... because when I was struggling in the first couple of weeks and she was struggling, we could introduce new people to each other that we thought that they would like and stuff. And that...that really helped*”.(P203/01:21:37)

Jane also received ES-CSS through ‘***scouts***’, ‘***guides***’, and ‘***track (athletics)***’, and her ‘***boyfriend***’. Jane said that her ‘***boyfriend***’ provided her with an opportunity to learn about socially appropriate behaviours. She explained how this experience provided her with ES-CSS which helped her to learn about socially appropriate behaviours, such as, “*… boundaries and...and what’s acceptable and what’s not acceptable and things like that. Because he had had relationships before I had them. I had more...like, more friendship than a relationship. So just educating me, what’s right, what’s wrong*”.(P203/01:27:37)

4.6.8 Procedural step 3

The categorical-form analysis (CFA) of Jane's data enabled me (the researcher) to gain in-depth insight into Jane's linguistic dialogue, namely her tones of voice and non-verbal communication. This was performed by using Jane's fabula notes and tagging frequency of nonverbal (sjuzet) occurrences within her narrative statements, using reflective diary entries. CFA data was categorised into forty-two varied tones, and nonverbals, and frequencies were calculated. CFA data relating to Jane's state of health positive and negative tones and non-verbals (n=23), were then used to illustrate tonal frequencies within her narrative. Table 4.4 (c) details fabula notes and tagged positive and/or negative nonverbal calculation for each CTT, which will be discussed in more detail in next sections (appendix 4.3 (a) details a breakdown of these calculations).

Table 4.3 (c): The positive and negative linguistic tones and nonverbals used by Jane during her interviews that were identified using the sjuzet data applied to statements made within the context of themes and subthemes.

		Percentage category occurrence of positive and negative linguistic tones/nonverbals in each CTT			
Tone or non-verbal used (frequency)	**Category (frequency)**	**Primary**	**Secondary**	**Sixth form**	**University**
excited (29) face lit up (5) upbeat (31) happy (19) relief (4) proud (43) grateful (32) smiling (87) laughing(9) fondness (11) amazed /awe (2)	**Positive** (226*)	12%	12%	>positive 50%	26%
sad (1) frustrated (4) annoyed (7) despondent (1) hopeless (2) disappointed (10) upset (3) angry (11) confused (6) vulnerable (1) withdrawn (7) terror (1)	**Negative** (47**)	26%	>negative 68% (>100% of the total angry tone used in this CTT) (>100% of the total negative-disappointed tone used in this CTT)	2%	4%

*Positive (-46 tones (11 excited, 5 face lit up, 6 upbeat, 6 happy, 4 relief, 3 proud, 4 grateful, 7 smiling) did not relate specifically to a CTT and have been excluded) (Total n=11)
**Negative (-7 tones did not relate specifically to a CTT and has been excluded) (Total n=12)
NB: Not included in this table were factual, serious, 'other' (quiet, matter of fact, emotional, contemplation, explanatory, timid, clapping, dramatic, loud, passive, assertive, shock, astonished, exaggerated (facial expression), softening, stubborn, wiggling) (Total tones n=19)
>Indicates the greatest frequency of tone type occurrence amongst all the CTTs

4.6.9 Procedural step 4

Holistic-form analysis (HFA) combined HCA, CCA, CFA results, using the HFA scoring matrix (chapter 3, section 3.6.6.3, table 3.3), to produce an HFA numerical score that could then be attributed to a CTT (calculation shown in appendix 4.3 (b)). This score was then compared with another CTT to gauge Jane's narrative progression or regression. HFA score also enabled consideration of the structure of Jane's narrative, how she positioned herself within it, her typology, cohesion within her narrative and any turning points. The 'overall' core of Jane's transitioning story showed a regressive, then progressive narrative (figure 4.3 (a)). The limitations of using a scoring matrix are discussed in section 6.7.

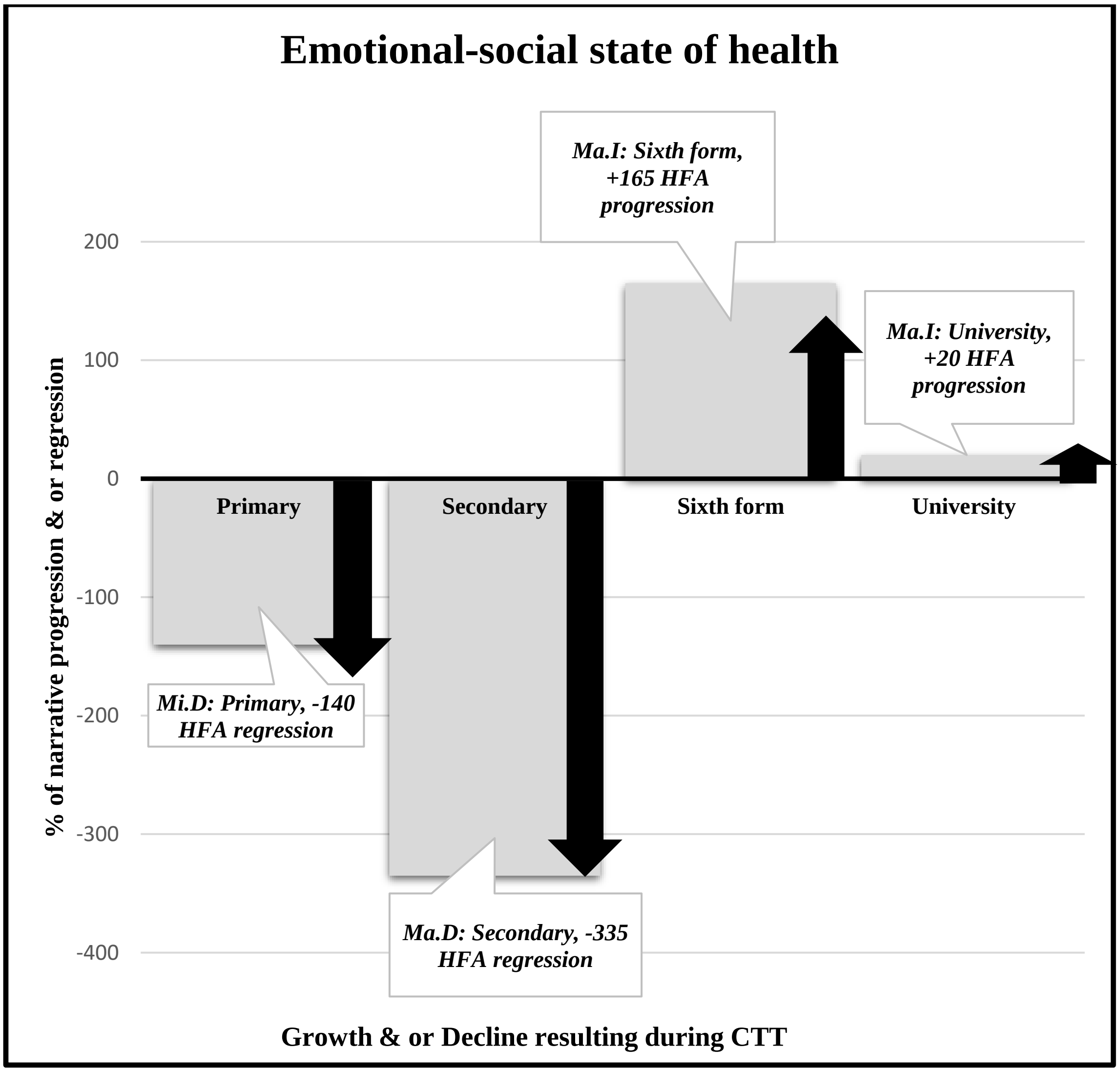


Figure 4.3 (a): Holistic-form: Narrative regression and progression of Jane's Core Story, CTT, TST, in relation to state of health. MiD = Minor deterioration in state of health / MaD = Major deterioration in state of health / MiI = Minor improvement in state of health / MaI = Major improvement in state of health

The primary CTT demonstrated -140 HFA regressive narrative decline (figure 4.3 (a) column 1). Jane’s data indicated that she experienced a minor deterioration in state of health (MiD) during this CTT due to increasing ES-CS.

The secondary CTT demonstrated -335 HFA regressive narrative decline (figure 4.3 (a) column 2). This CTT had the greatest occurrence of CFA minor negative-disappointed tones when discussing Ac-CS, Ac-CSS, ES-CS, experiences compared with other CTT (table 4.3 (c)). These tones were classified as minor negative CFA tones and is thus suggestive of a negative experience. This CTT also has the greatest occurrence of major negative-angry tones discussing Ac-CS and ES-CS, and major negative (overall) tones discussing Ac-CS, Ac-CSS, ES-CS and SnC CS, experiences, compared with other CTT (table 4.3 (c)). Thus, Jane’s data indicated that she experienced a major deterioration in state of health (MaD) during this CTT due to a major increase in ES-CS, ‘**anxiety**’, ‘**emotional mental health**’ (‘**anorexia**’, ‘**self-harming**’, ‘**suicide attempts**’), and ‘**being bullied**’.

The sixth form CTT demonstrated +165 HFA progressive narrative growth (figure 4.3 (a) column 3). This CTT had the greatest occurrence of CFA major positive tones discussing Ac-CS, ES-CS, EST, SnC, and CSS experiences, compared with other CTT (table 4.3 (c)). Jane’s data indicated that she experienced a major improvement in state of health (MaI) during this CTT due to major improvement in ES-CS, implying that she overcame previous CS, with ‘anorexia’, ‘trichotillomania’, ‘suicide attempts’ stopping, and ‘self-harming’ incidents lessening. This was likely to be due to the Ac-CSS and ES-CSS, ‘***autism specific***’ CSS, that accompanied her autism diagnosis (aged 16 years) as well as ADHD, anxiety, and dyslexia diagnoses.

The university CTT demonstrated +20 HFA progressive narrative growth (figure 4.3 (a) column 4). Jane’s data indicated that she experienced a major improvement in state of health (MaI) during this CTT due to no ongoing increase in ES-CS, implying that she overcame previous CS or that these were considerably reduced.

4.6.9.1 Jane’s Typology

HFA revealed Jane’s typology changed drastically throughout her narrative. In the earlier educational CTT of Jane’s narrative, she demonstrated a ‘victim’ typology, helpless to the perceived maltreatment that she received from her peers and teachers during primary and secondary CTTs, whom she appeared to feel victimised by. From sixth form onwards, following her diagnoses, she became the ‘hero’ in her story, overcoming many of her challenges and difficulties through determination. Typology will be discussed in detail in step 6, section 4.6.11.

Table 4.3 (d): Calculation of Jane’s Holistic-form analysis score combining HCA, CCA, CFA narrative data. HCA = holistic-content analysis, CCA = categorical-content analysis, CFA = categorical-form analysis, HFA = holistic-form analysis, CTT = core transitioning theme, CS = concurrent stressor, Ac = academic, ES = emotional-social, MiD = minor deterioration to state of health, MaD = major deterioration to state of health, MiI = minor improvement to state of health, MaI = major improvement to state of health

	Holistic-form analysis frequency and score							
	Primary		**Secondary**		**Sixth form**		**University**	
(i) Previously identified CS	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**
Major Ac-CS (impacting state of health) $^{(f \times -5)}$	f = 1	n = - 5	f = 1	n = - 5	f = 1	n = - 5	f = 1	n = - 5
Minor ES-CS $^{(f \times -5)}$	f = 11	n = - 55	f = 15	n = - 75	f=12	n = -60	f=11	n = - 55
Major ES-CS $^{(f \times -10)}$	f = 3	n = - 30	f = 3	n = - 30	f = 2	n = - 20	f = 2	n = - 20
(ii) CFA linguistic (nonverbal) results	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**
Minor negative CFA $^{(f \times -25)}$	-	-	f = 1	n = - 25	-	-	-	-
Major negative CFA $^{(f \times -50)}$	-	-	f = 2	n = -100	-	-	-	-
Minor positive CFA $^{(f \times +25)}$	-	-	-	-	-	-	-	-
Major positive CFA $^{(f \times +50)}$	-	-	-	-	f = 1	n = +50	-	-
(iii) State of health	**Category (HFA total score)**		**Category (HFA total score)**		**Category (HFA total score)**		**Category (HFA total score)**	
MiD $^{(f \times -50)}$	n = - 50		-		-		-	
MaD $^{(f \times -100)}$	-		n = -100		-		-	
MiI $^{(f \times +50)}$	-		-		-		-	
MaI $^{(f \times +100)}$	-		-		n = +200 (x2)		n = +100	
	Total primary HFA score		**Total secondary HFA score**		**Total sixth form HFA score**		**Total university HFA score**	
	n = - 140 (regressive narrative decline)		n = - 335 (regressive narrative decline)		n = + 165 (progressive narrative growth)		n = +20 (progressive narrative growth)	

4.6.10 Procedural step 5

To be able to illustrate to the reader Jane’s ability to adapt to a CTT, I encompassed Jane’s HCA, CCA, CFA, HFA data into the ‘educational transitioning model’, which visually detailed; (1) any CS that impacted her state of health, (2) ‘self’ characteristics, (3) concurrent stressor support (CSS), (4) previous CTT state of health compared with current state of health. The educational transitioning models (figures 4.3 (b)-(f)) summarise Jane’s lived experiences and educational journey in relation to her state of health.

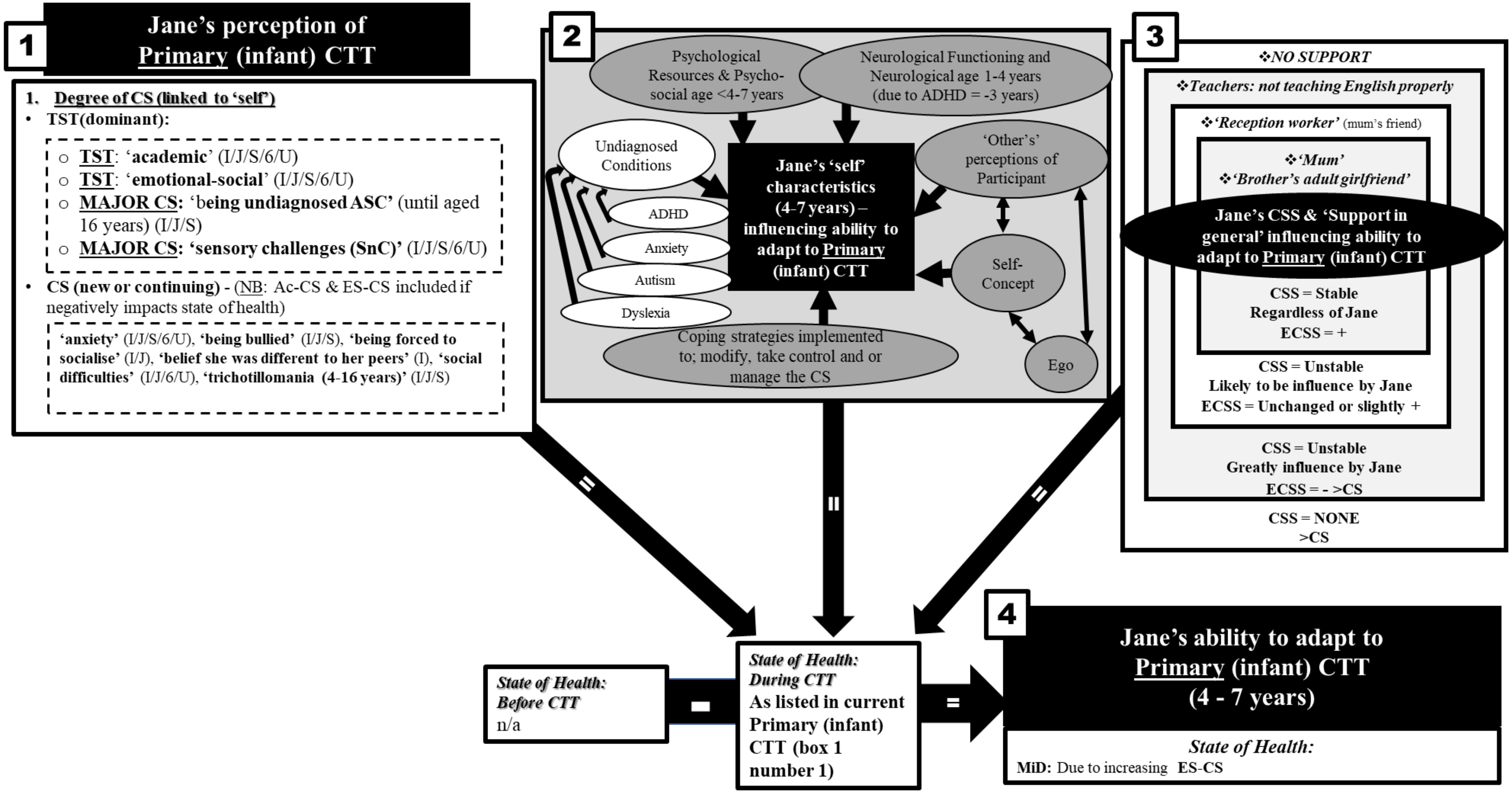


Figure 4.3 (b): Educational transitioning model representing Jane's ability to adapt to the primary (infant) CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

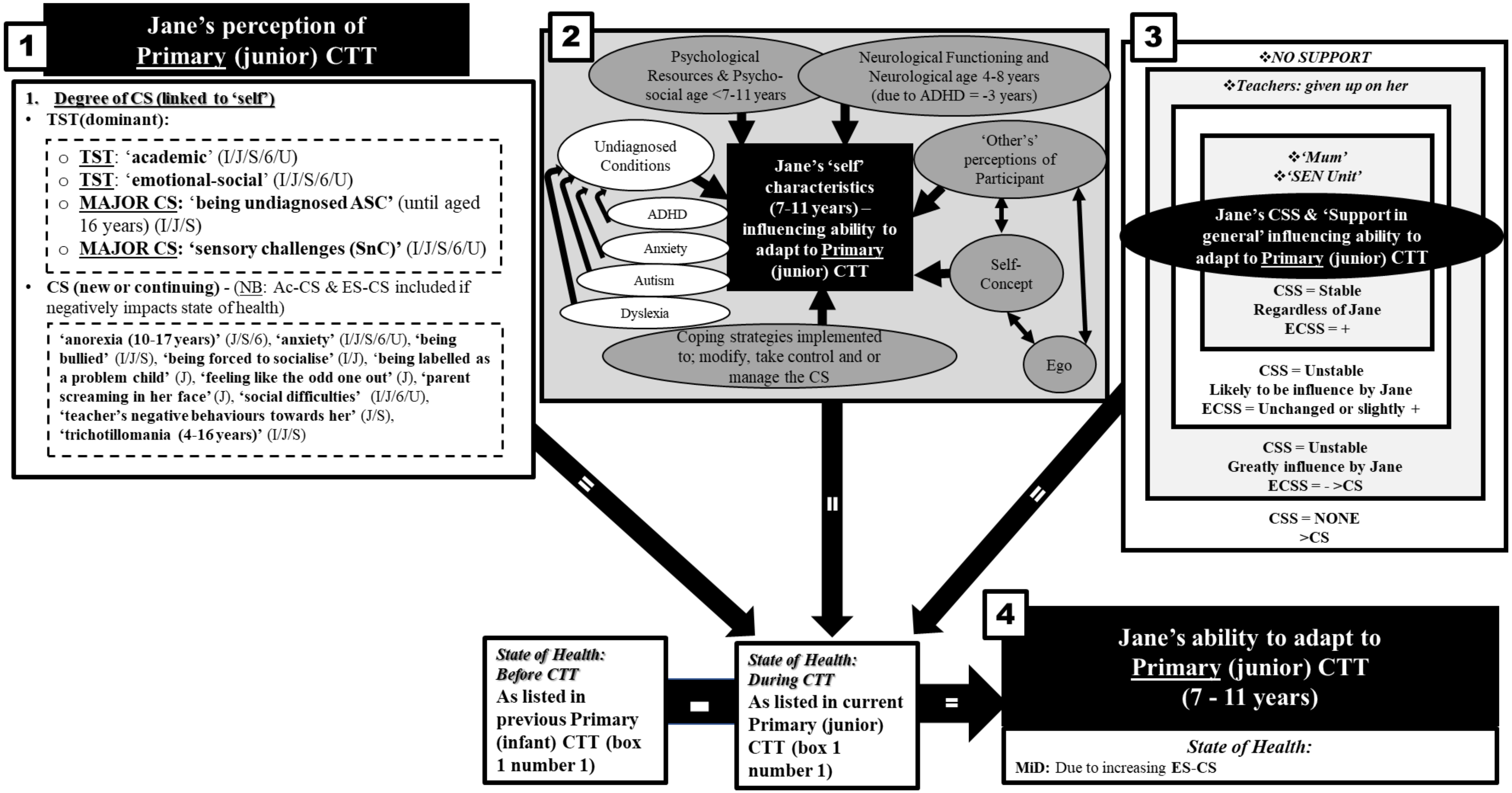


Figure 4.3 (c): Educational transitioning model representing Jane's ability to adapt to the primary (junior) CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

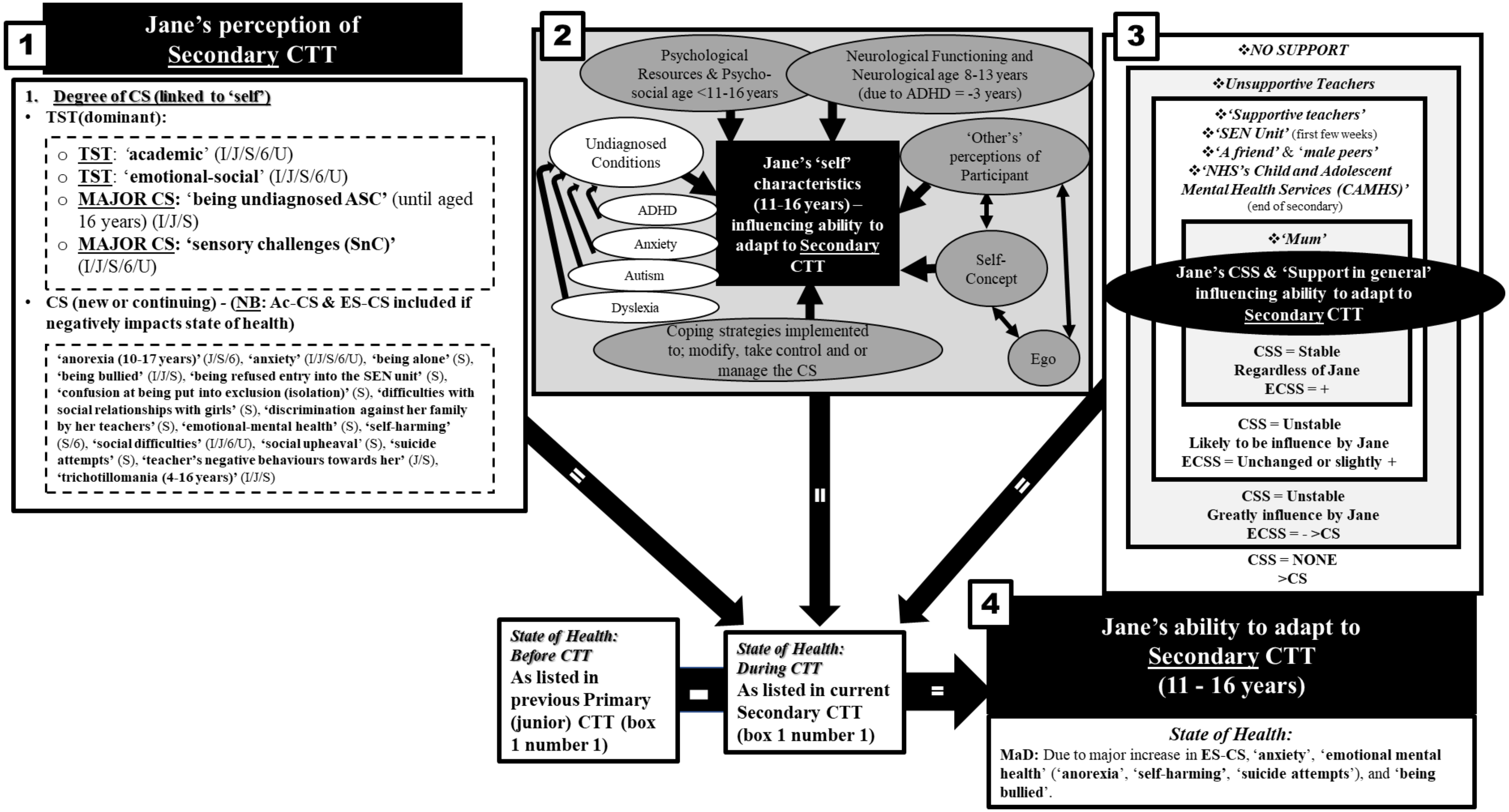


Figure 4.3 (d): Educational transitioning model representing Jane's ability to adapt to the secondary CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

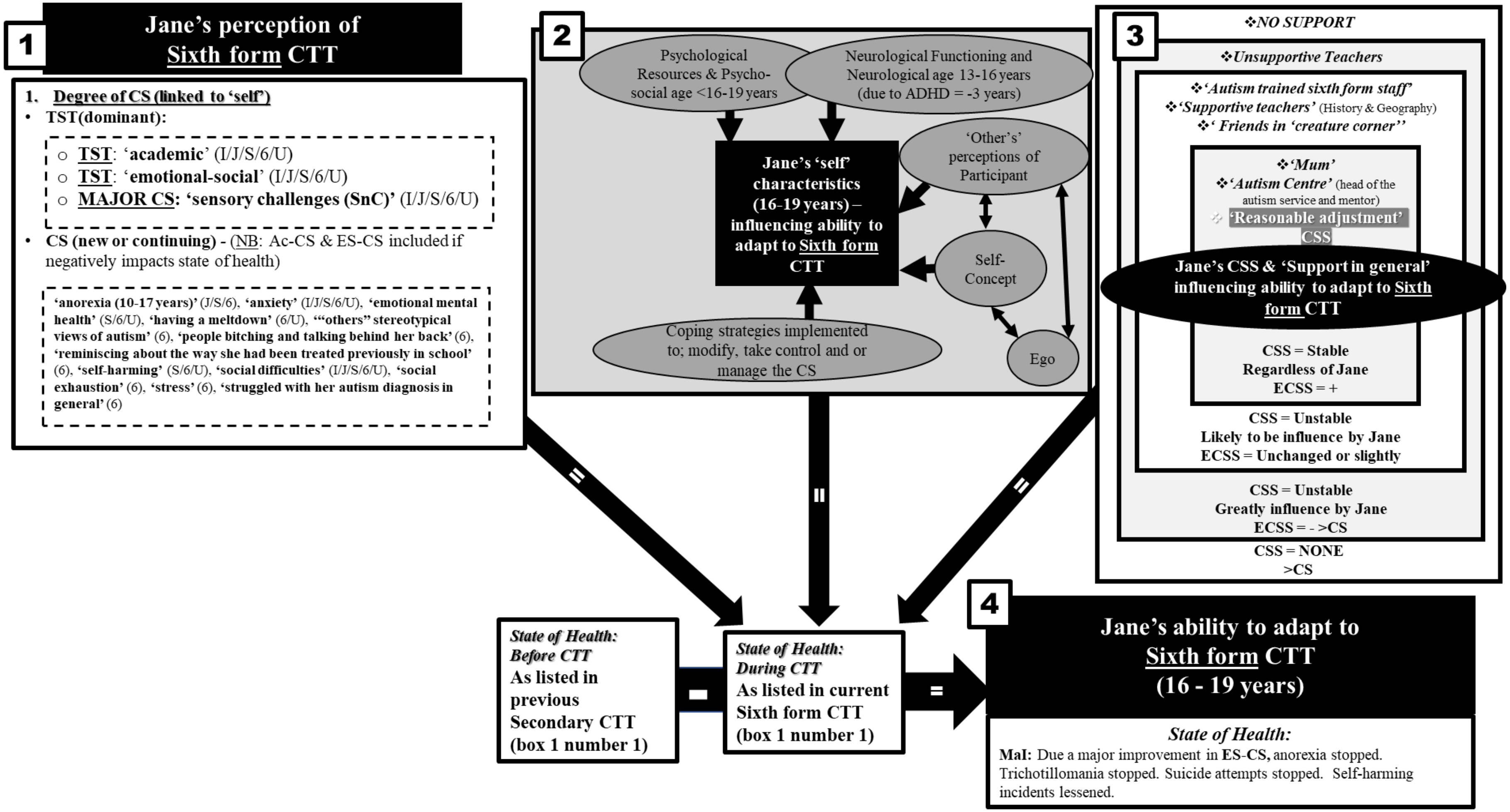


Figure 4.3 (e): Educational transitioning model representing Jane's ability to adapt to the sixth form CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268]
For abbreviations see chapter three, table 3.4.

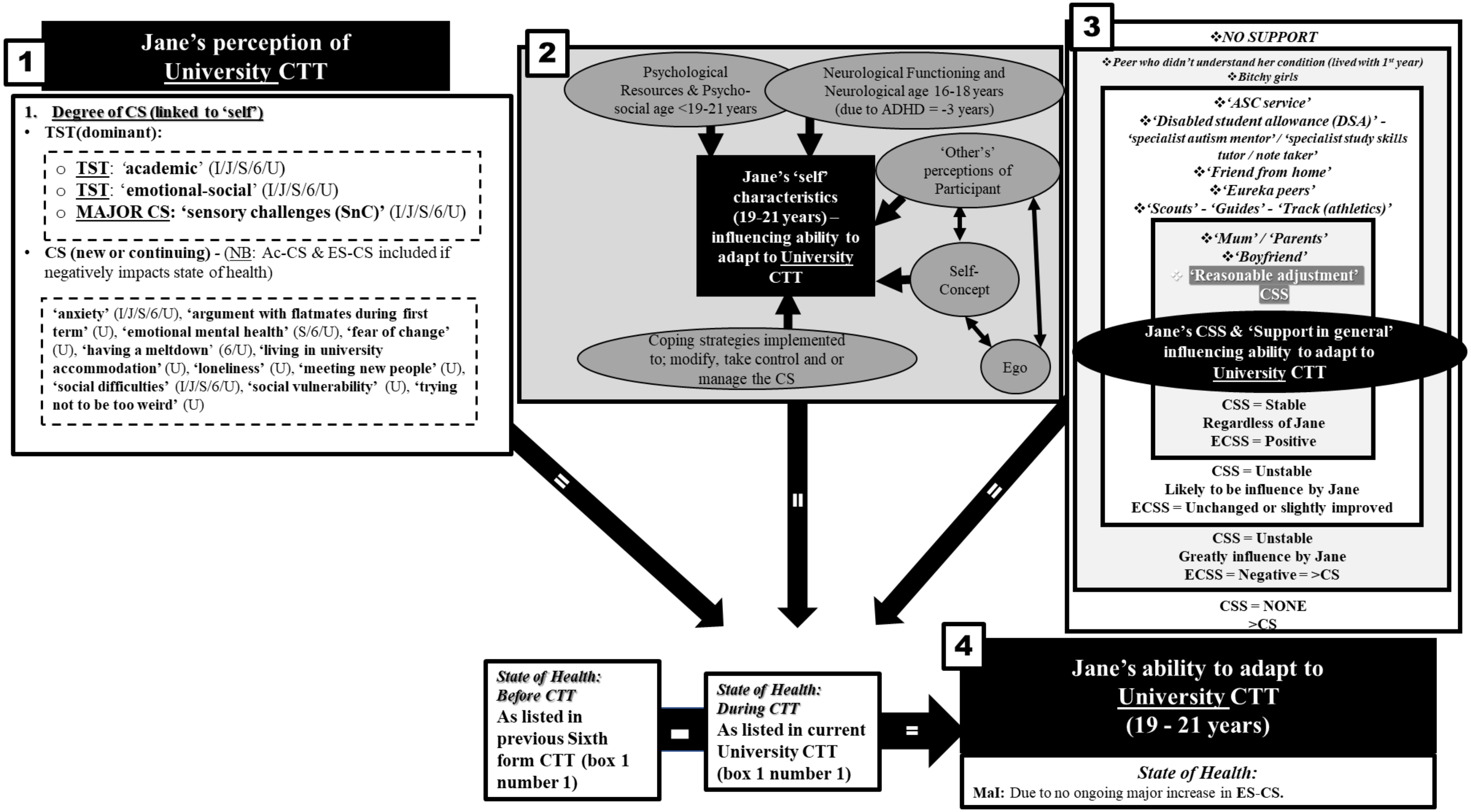


Figure 4.3 (f): Educational transitioning model representing Jane’s ability to adapt to the university CTT. (1) Degree of CS experienced during CTT, (2) Influence of ‘self’ characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

4.6.11 Procedural step 6

Critical narrative analysis (CNA) considers the functionality of Jane’s story, how she is positioned within it, by considering the fabular and sjuzet properties reflecting her; thoughts, feelings, emotions, actions, interactions, achievements, challenges, and the social structure in which her story takes place. CNA identified a critical positioning theme; namely Jane as an ‘agent for positive autistic change’.

4.6.11.1 Jane’s positioning as an ‘agent for positive autistic change’

In the secondary CTT, prior to her diagnoses Jane consciously, and/or subconsciously, we saw the positive development of Jane becoming an ‘agent for positive autistic change’ in her own life in the context of the CS she was experiencing (academically, emotionally, socially and sensorially), by instigating or being involved in situations such as aggressively responding to her peers in class so that she would be forced to leave her lesson and be put in isolation. She was actively the ‘agent of her individual positive autistic change’ resilient in overcoming CS by directly influencing the change in environment from an autism challenging one to a more positive situation where the CS she was experiencing were no longer present. Albeit through, what some might term ‘negative behaviours’. In her final year at secondary school Jane severely self-harmed and deliberately attempted to aggravate the wound as a suicidal attempt which resulted in hospitalization, eventually resulting in much needed mental health (MH) interventions and her anxiety and ASD (ADHD) diagnoses. Again, Jane demonstrated herself as her own ‘agent’ for positive autistic change, her conscious behaviours and/or subconscious behaviour, directly influenced a major life changing event, she went from being viewed as a ‘non-autistic’ individual to becoming an ‘individual with autism’ with recognised needs that would now be supported. In sixth form, Jane continued in her role as an ‘agent of positive autistic change’ with growth in her self-advocacy skills, when she was voted a student ambassador, as ‘student of the future’. This has resulted in her regularly returning to her sixth form college to deliver talks about autism, as well as being involved in training student doctors about the needs of autistic individuals.

The final CTT of Jane’s narrative took place in the second year of her university degree, whereby she continued to demonstrate her self-advocacy skills, through her active role as an ‘agent of positive autistic change’. Reprimanding lecturers when students with autism needs weren’t being met, as well as educating her peers, boyfriend, about autistic ‘meltdowns’, comparing them to a computer crashing, emphasising the vast value, like computers, that individuals with autism have in society. Finally, Jane continued to be an ‘agent’ of positive autistic change by sharing her narrative with me (the researcher) through the medium of this thesis, with her continued presenting intention to positively change other’s understanding about autism.

4.6.12 Jane’s ability to adapt to change

Figure 4.3 (g), an adaptation of Ellaway et al[263] theoretical model demonstrates how adapting to ‘***change***’ was complex for Jane during her transition from primary to secondary school, and then on to sixth form college. In her primary school she had emotionally-socially ‘***performed***’ (interacted with peers during breaktimes) within the safety net of the special educational needs (SEN) department.[263] When she arrived at her secondary school, she was provided with SEN support, with an initial slight decline in her emotional-social performance as she settled into school life, before returning to her original emotional-social performance level, commenting on how she met ‘likeminded people’ and made a ‘best friend’. After several weeks in secondary school Jane was refused access to the SEN department, due to not having an ASC diagnosis. This change resulted in her emotional-social performance level dropping dramatically due to her being expected to emotionally-socially ‘***perform***’ (interact with peers during breaktimes) in the main school setting, which she was unable to do due to her considerable social-communication and interaction skill deficits. Her peers, and some teachers, began to bully her.

As outlined in figure 4.3 (g), it was difficult for Jane to be resilient and return to her original emotional-social ‘***performance***’ level in her secondary phase without SEN support which required a diagnosis. Following a severe deterioration in her mental health, including a suicide attempt, Jane was diagnosed with autism. Following this autism diagnosis, Jane experienced a ‘***recovery time***’ period, during which she started sixth form college. Even when Jane’s sixth form college provided her with SEN support she still did not reach her original emotional-social performance level, needing a prolonged period, to leave sixth form and return a year later, to '***recover***'. When Jane returned to sixth form, with continuing SEN support, she demonstrated that she reached her original emotional-social performance level, through resilience and positive self-advocacy skills which enabled her to go on to exceed this level, making lifelong friends, with no reoccurrence of suicide attempts.

This change theory model demonstrates the impact of all contextual factors when a '***change***' occurred for Jane, including whether any support measures were in place or not, and the influence that this may have on her. Jane's results evidenced that the impact of changing educational provider was not a simple or straight forward change concept based on whether she had 'SEN support' or not, that by providing SEN support she would simply return to her original emotional-social performance level, as many other factors, such as those outlined in the aforementioned findings also influenced her.

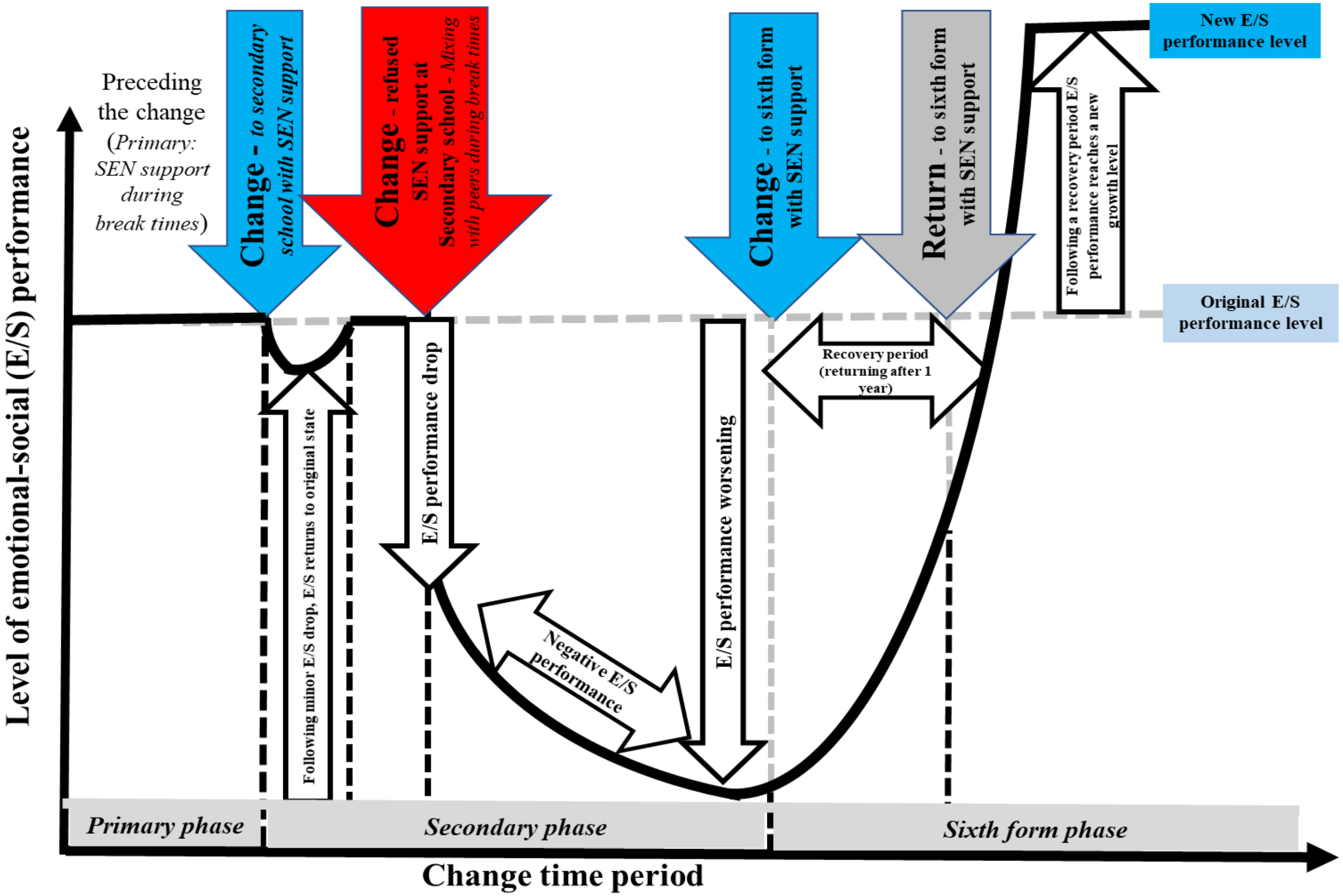


Figure 4.3 (g): How change impacted the emotional-social performance of Jane and role played by support provisions. Adapted from:[263]

4.6.13 Summary of Jane’s ability to adapt to each core transitioning theme

HCA: CTT; primary (infant and junior), secondary, sixth form, university.
CCA: TST; academic (Ac), emotional-social (ES).
CFA: Greatest occurrence of minor negative-disappointed tones during secondary CTT. Greatest occurrence of major negative-angry and negative overall tones during secondary CTT. Greatest occurrence of major positive tones during sixth form CTT.
HFA: Indicated a regressive-progressive narrative.
HFA & CNA: HFA linguistical analysis and CNA revealed a transformation throughout her narrative from a ‘victim’ typology, during her primary and secondary CTT, towards a ‘hero’ typology, during her sixth form and university CTT. Becoming an ‘agent for positive autistic change’, by the end of her sixth form CTT.

HCA, **CCA**, **CFA**, **HFA**, **combined (table 4.3 (d)):**

Primary CTT, evidences a regressive narrative. Evidence of good support practice took the form of: Stable CSS (regardless of behaviour) was provided by ‘***Mum***’, ‘***brother***’***s adult girlfriend***’ (infant) and ‘***SEN unit***’ (junior), unstable positive CSS (influenced by behaviour) and by ‘***reception worker***’ (mum’s friend in infants). Data indicated a minor deterioration in state of health evidenced by an increase in ES-CS.
Secondary CTT, evidences a regressive narrative. This CTT had the greatest overall HFA narrative regression, compared with other CTT. This CTT had the greatest occurrence of CFA minor negative-disappointed tones, suggestive of negative experiences, compared with other CTT. This CTT had the greatest occurrence of CFA major negative-angry and negative overall tones compared with other CTT. Evidence of good support practice took the form of: Stable CSS continued to be provided by ‘***Mum***’, unstable positive CSS was provided by ‘***supportive teachers***’, ‘***SEN unit***’ (in the first few weeks), ‘***a friend***’, ‘***males peers***’, and ‘***NHS***’***s Child and Adolescent Mental Health Services (CAMHS)***’ (end of secondary CTT). Data indicated a major deterioration in state of health evidenced by a major increase in ES-CS, ‘**anxiety**’, ‘**emotional mental health**’ (‘**anorexia**’, ‘**self-harming**’, ‘**suicide attempts**’), and ‘**being bullied**’.

Sixth form CTT, evidences a progressive narrative. This CTT had the greatest occurrence of CFA major positive tones compared with other CTT. Evidence of good support practice took the form of: Stable CSS continued to be provided by ‘***Mum***’, the ‘***autism centre***’ (head of the autism service and mentor). Unstable positive CSS was provided by ‘***autism trained sixth form staff***’, ‘***supportive teachers***’, and ‘***friends in*** ‘***creature corner***’’. Data indicated a major improvement in state of health evidenced by a major improvement in ES-CS implying that she overcame previous CS (‘anorexia’, ‘trichotillomania’, and ‘suicide attempts’ stopping, ‘**self-harming**’ incidents lessening), being diagnosed and by increased ‘***autism specific***’ CSS provided by the ‘***autism centre***’ which included ***reasonable adjustments***’.

University CTT, evidences a progressive narrative. Evidence of good support practice took the form of: Stable CSS continued to be provided by ‘***Mum***’, in addition to this by her ‘***parents***’ (including Dad), and her ‘***boyfriend***’. Unstable positive CSS was provided by the ‘***ASC service***’ and through ‘***Disabled student allowance (DSA)***’ in the form of a ‘***specialist autism mentor***’, ‘***specialist study skills tutor***’, ‘***note taker***’. Jane also received CSS from a ‘***friend from home***’, ‘***Eureka peers***’, and through ‘***Scouts***’, ‘***Guides***’, and ‘***Track (athletics)***’. There was a continuation of ‘***reasonable adjustments***’ CSS. Data indicated a major improvement in state of health evidenced by no ongoing increase in ES-CS, implying that she overcame previous CS or that these were considerably reduced.

4.7 Leigh’s story

4.7.1 Background and setting

The initial participant interview with Leigh took place in his family home, where he was living with his mum and dad, two dogs and a cat. At the time of the interview Leigh has just successfully completed a MSc in conservation and environmental management.

4.7.2 Procedural steps 1-2: Overview

The holistic-content analysis (HCA) of Leigh’s data is reflected in table 4.4 (a), the core transitioning themes (CTT) that emerged from his educational journey narrative. Two overarching TSTs were identified, namely ‘**academic**’ (Ac) and ‘**emotional-social**’ (ES). The ‘**emotional-social**’ (ES) subtheme has been grouped to include CS related to this heading such as; bullying, discrimination, friendship, group interactions, mental health (e.g., anxiety, fears, phobias, self-harm, stress), social anxiety, stigma, and so on.

Table 4.4 (a): Holistic-content analysis overview: Leigh’s core transitioning themes (CTT) and transitioning sub-themes (TST). His age during each CTT is indicated within the brackets.

	Core transitioning themes (CTT)				
	Primary school (4-11 years)	**Secondary School (11-16 years)**	**Sixth form (16-19 years)**	**University (BSc) (19-22 years)**	**University (MSc) (22-23 years)**
Transitioning sub-themes (TST)	Academic (Ac) Emotional-Social (ES)				

The categorical-content analysis (CCA) of Leigh’s data, enabled a more in-depth examination of each CTT to look for patterns. For each CTT, Leigh’s narrative was examined for the appearance of the specific concurrent stressors (CS) experienced by him (table 4.4 (b)) with the sections that follow giving context and describing them in detail. In the primary and secondary CTTs their appearance appeared to be exacerbated by the overarching or major ES-CS ‘**being undiagnosed ASC**’ which was likely to have had impacts on both the ‘**academic**’ (Ac) CS and ‘**emotional-social**’ (ES) CS.

It is important to note that there was evidence of difficulties with memory recall. For example, when asked if his primary school were involved in supporting his transition to secondary school, he became quite flustered and unable to recall their involvement.

> "*I'm not sure the primary school was involved a lot because I don't think I don't know if I received… I can't*...(pause)...*sorry. I'm worried that I might be contradicting myself but I'm not sure*".(P204/00:27:52)

> "*Vague memories. I remember the place where the place where the youngest group was. There was a playgroup nearby and I do have one or two fleeting memories of that but it's just so brief that I can't really... It's vague. It's very vague*".(P204/00:08:26)

Thus, due to difficulties with episodic memory, it has been vital to include Leigh's parent's perspective about his experiences, particularly in the context of his early primary school memories.

Table 4.4 (b): Categorical-content analysis overview: Leigh's transitioning sub-themes (TST) and concurrent stressors (CS). Table also shows the core transitioning themes (CTT) or timepoints where the CS occurred. P = primary, S = secondary, 6 = sixth form, UBSc = undergraduate university, UMSc = postgraduate university

Transitioning sub-themes (TST)	**Concurrent stressors (CS)**	**Time point(s)**				
		P	**S**	**6**	**UBSc**	**UMSc**
	Major CS: 'being undiagnosed ASC' (until aged 14 years) **(Un)**	**P**	**S**			
	Major CS: 'worrying about others'	**P**	**S**	**6**	**UBSc**	**UMSc**
'academic' (Ac)						
	'A-level exams'			**6**		
	'academically slow in English'	**P**				
	'difficulties following instruction'	**P**				
	'having to learn about topics he was not interested in'		**S**			
	'his computer crashing'				**UBSc**	
	'leaving work to last minute'				**UBSc**	
	'math'	**P**	**S**			
	'rigid need to complete a piece of work in a certain manner'	**P**				
	'running out of time'	**P**	**S**	**6**	**UBSc**	**UMSc**
	'running out of time even with 25% extra time being given'		**S**	**6**		
	'statistical analysis'					**UMSc**
	'the jump from GCSE biology to A-level biology'			**6**		
	'the most challenging assignments he had ever done academically'					**UMSc**
'emotional-social' (ES)						
	'a phobia about world news'				**UBSc**	**UMSc**
	'a phobia of filling out forms'				**UBSc**	**UMSc**
	'a phobia of paying bills'				**UBSc**	**UMSc**
	'anxiety about world affairs'				**UBSc**	**UMSc**
	'being bullied'	**P**	**S**			
	'being dismissed by peers'		**S**			
	'being ignored by his peers'		**S**			
	'being severely short-sighted'	**P**				
	'being shouted at by his peers'		**S**			
	'being told to shut up by his peers'		**S**			
	'feeling different to his peers'	**P**	**S**			
	'feeling downtrodden'		**S**			
	'feelings of shame that he was not able to stand up for himself'		**S**			
	'having to take on the responsibility of paying the household bills'				**UBSc**	
	'his clothes being torn'	**P**				
	'loneliness'	**P**				
	'needing to be reminded to eat during a primary school trip'	**P**				
	'peers who did not want to learn in class'		**S**			
	'social difficulties with peers'		**S**			
'emotional-social transitioning' (EST)						
	'being forced to have a shower during P.E.' (worried about…)		**S**			
	'social difficulties with peers' (worried would continue)				**UBSc**	

4.7.3 Procedural steps 1-2: Primary CTT

4.7.3.1 The major concurrent stressor ‘being undiagnosed ASC’ (Un-CS)

Leigh’s parents appeared to become aware of his autism during his primary CTT, although it was something he was not yet aware of.

> “*I can’t remember exactly. I think it was around eight or nine when my parents were told by someone at my primary school that I was probably on the spectrum*”.(P204/00:00:57)

His mum stated that autism was first suspected when he was in year one (aged 5/6 years), “*I would say things started manifesting themselves in year one*”.(PFM204/00:03:31) It must be noted that some detailed memories, shared by Leigh demonstrate autistic characteristics, such as his first clear memory of primary school which was object specific, with him describing the room, the toys played with, placing particular emphasis on the spinning and pouring toys, rather than mentioning his peers.

> “*... First clear memory, I think it was when I was in year one ... it was all one big room, and they had all these things like they had these big sort of tubs full of sand and all these...*(pause)*... a funnel and a windmill and you poured water through it and it would spin around I think*”.(P204/00:08:54)

Un-CSS (Evidence of good support practice)

Leigh’s artistic, storytelling, strengths were put to good use when he was eight and drew postcards of his favourite animals to sell in zoos. Jersey zoo’s Lee Durrell offered to sell Leigh’s cards in their zoo. This incident resulted in Leigh forming a lifelong connection with ‘***Lee Durrell***’ and receiving CSS from her, later doing a DICE (Durrell Institute for Conservation and Ecology) BSc, with her CSS influencing his educational journey from that moment on.

> "*…Well, I've met her when I was eight because when I… because when I designed a set of cards featuring various animals and my dad printed it, sold those in his shop, in the shop and they did really well, and he tried to get them to various zoos around the country, but none of them would take them and only when he tried Jersey Zoo that he finally got a yes and yeah, Lee Durrell invited us down*".(P204/00:59:00)

4.7.3.2 Academic concurrent stressors (Ac-CS)

In primary school Leigh felt that he got on, "*…academically not too bad*", particularly enjoying, "*things like history, geography, the humanities those are the ones I liked best*".(P204/00:15:17) However, Leigh shared that he experienced Ac-CS due to being '**academically slow in English**'.

> "*With English that was the one I got rated for being slow the most … we would have this whole set of questions about…*(pause)*…we'd have three sections varying in difficulty. The first were very easy ones relating to the main topic. I can't remember exactly the second section, but that was kind of a bit higher up and then the last one, the trickiest, was the one that that was very much where we have to use our creativity the most for this, but I don't think I ever managed to get to the second section for each of those in our lessons*".(P204/00:15:17)

Leigh gave a detailed and humorous description of a mistake made during a math exercise as his first academically related memory, emphasising Ac-CS because of '**difficulties following instruction**' and a '**rigid need to complete a piece of work in a certain manner**'.

> "*In terms of things like math and such and problem solving it would be these, sort of big flimsy books … with big cartoons characters, and such, and then we'd have to fill those in, and I remember doing one of those books. I think it was kind of like math-ish based whereas it had this sort of space setting and you had these I think like astronauts and aliens and whatnot and you'd have instructions. The characters were in blank and you had to colour them in, certain ones. For example, colour the one of top, colour the one on the side and*

> *this and that. Well anyway I was quite into colouring, but I didn't really want to see any of them left blank, so I coloured them all in… And I still remember it. When we got them back from being marked it was just a scribble saying, "You've coloured them all"…".*(P204/00:11:00)

When asked what the most challenging subject in primary school was, Leigh expressed CS with '**math**'.

> "*I was terrible. I mean I managed to score highly enough to get through things like the SATs* (Scholastic Assessment Test)… *I always found that … a grind math. It was always a challenge even …* (pause)… *I always found it a real challenge, so I'd always have to ask mum to help with homework, because she was the best at math. But God, I really hated math*".(P204/ 00:17:43)

The first exams that Leigh remembered doing were his scholastic assessment test (SATs) in his last year at primary school, he stated that he experienced Ac-CS due to '**running out of time**'.

> "*Well, we did that* (SAT's) *in the classroom. It mostly felt like pretty much every exam, but it's just this complete silence, sitting in a stuffy room, trying to fill in every space with an answer. So, in my early days I don't think I did fill every space*".(P204/00:18:51)

<u>Ac-CSS</u> (Evidence of good support practice)

Leigh recollected that there was '***a teaching assistant***' who provided additional support to all children in his class.

> "*I think there was someone who helped out. I think she actually also went on to work at my secondary school because it wasn't too far away. But of course, she had several responsibilities… there were other children who had similar difficulties to me and I* (sigh) *well I couldn't have help full time*" (P204/00:17:10)

Not accepting Ac-CSS

When asked if he received Ac-CSS in primary school Leigh said that he thought that there was support available to him, but he preferred to sort things out himself and didn't tend to use it.

> "*I think people were there, but I tended to keep it to myself*".(P204/00:21:55) "*Well, it's not that no support was available … it's just I tended to… see how well I could do on my own*".(P204int-2/00:14:49)

4.7.3.3 Emotional-social concurrent stressors (ES-CS)

Leigh optimistically described socialising in primary school as not being "*too bad*" , "*mostly ok*", for him and talked about his, "*… one best friend…* 'S' *… I think he'd been my best friend since I started primary school*".(P204/00:19:42) He positively described his solitude in the playground during his primary school years, smiling he reminisced about his imaginative play and being, "*perfectly, perfectly happy*".(P204/00:23:04)

> "*Well break times everyone else went off and interacted with each other. I just mostly wondered around the playground and just making up things in my head. I had...*(pause)*...just letting my imagination go free, imagining different scenarios, with characters that I'd brought up... So, I mean I still do now but some of them I'll write it down. So that's something that I've always been doing for a long time … Yeah, and I had a tendency to daydream a bit as well. So at least there I could do it as much as I wanted. … But I was always very much solitary during my break times... I was perfectly, perfectly happy as it was*".(P204/00:23:04)

However, concerns were voiced by both parents in sad tones about Leigh having negative memories of primary school and ES-CS due to '**feeling different to his peers**'. Leigh, who has echolalia, a less common co-occurring condition for autism, described reciting dialogue, which he found satisfying, reflecting that he may have started doing this because of spending a lot of time on his own, how hearing his own voice reciting dialogue alleviated his '**loneliness**' CS.

> "*...I think I have something called echolalia. I don't know for certain that that's what it is, but when I'm on my own I'll often find myself reciting all the dialogue from a TV programme that I've seen or a YouTube video, things like that. I've been doing it I think…* (pause)*… certainly since secondary school, probably before then. I have no idea why. I don't know. It could that it just gives me... I kind of enjoy repeating dialogue that I like that sounds satisfying to say. It could be that came about through being on my own a lot of the time. I guess one of the main things with Asperger's was I had quite a lot of …few problems… fitting in from a social perspective, so from a time alone I just began repeating things and just the sensation of hearing those voices kind of alleviated a loneliness*".(P204/00:06:00)

He went on to state, "*...I have always been fairly content with my own company. Since I was a kid, my best friends have been books, well aside from* 'S' *of course*".(P204/00:50:35

When asked to describe how he got on socially in primary school Leigh stated, "*mostly it was ok*",(P204/00:19:51) looking incredibly sad as he said this. Leigh went on to describe how he suffered ES-CS because of '**being bullied**', that he was called demeaning names, how he let, "*…their word cut me*",(P204/00:20:27) and how there were occasions when he experienced, '**his clothes being torn**' CS.

> "*Mostly it was okay. That being said I did find myself teased a fair bit as well and some gave me demeaning nicknames and a fair number of them were kids who were younger than me, so I found…*(long pause – unable to continue with his answer)*… Getting upset mostly. I've never been particularly confrontational. I just, well, let their words cut me really which is not the kind of thing you want to do. I remember there was one kid at primary school, and he'd be really rough. He'd tear my clothes and whatnot and my dad went and spoke to the teacher, the head teacher, but...*(pause)*...well I don't know if he was the headmaster but one of the….yeah, deputies, but he was no help at all. He just said well this other kid who was ripping clothes he said he had problems himself… That was no excuse for him to go tear my clothes, so my dad then went and spoke to the kid's mum and she was much more helpful, and the kid actually apologised...It did stop*".(P204/00:21:19)

Leigh and his parents recalled a key significant event which triggered, '**needing to be reminded to eat during a primary school trip**' CS, which highlighted that Leigh had additional needs that were not being supported by the primary school, who had allowed him to go the entire day without food.

> "*Okay. I can't remember how old I was. I think I was six or seven when this happened, maybe a bit younger but we had a school trip that we took packed lunches on and my mum made me a packed lunch and put it right in my rucksack and then we went off on this trip. I can't remember where it was to. I've heard this from my parents, so I don't remember it honestly but anyway later they got a call from the school that I was in a really bad state because when we got back, I was just on the ground crying and grumbling. I don't know. It turns out I was just really, really hungry because I'd forgotten about the packed lunch and I didn't realise I had it with me*".(P204/00:12:06)

Emotional challenges didn't appear to be something that Leigh felt he struggled with during his primary years, describing that he didn't tend to worry about himself instead '**worrying about others**', which appeared to cause considerable ES-CS which worsen throughout his narrative.

> "*I don't think I was particularly prone to extreme emotions. I do remember being in fights a couple of times, but it was nothing particularly out of the ordinary ... I was kind of a worrier sometimes, and it kind of got worse when I was a bit older ... things like when my mum and my dad went off somewhere and I was worried there might be an accident or something. I suppose I did feel of that throughout my school years, but it was things that affected people who were close to me. I didn't tend to worry*".(P204/00:23:44)

Finally, Leigh and Mum both cited a major difficulty that resulted in CS, '**being severely short-sighted**', how it took 3 years before it was noticed and diagnosed.

> "*The teachers didn't really notice that I was short-sighted either. That came about I think I was seven or eight at the time. I do remember having trouble just looking at the board having to squint a lot, but of course I didn't know what was vision, so it was only because my mum worked as a teaching assistant ... there that she realised that every time say it was written down I'd always be there*

> *squinting, trying to see what it said and the teachers never bothered to let her know about that. So, she took me to the opticians*”.(P204/00:13:41)

ES-CSS (Evidence of good support practice)

During primary school ‘***Mum***’ and ‘***Dad***’ provided ES-CSS, in addition he received ES-CSS from his ‘***best friend*** ‘***S***’’. Leigh also shared that his ‘best friend’ was ‘***his books***’, which appeared to provide him with considerable ES-CSS.

> “*Since I was a kid, my best friends have been books*”.(P204/00:50:35)

No ES-CSS

Sadly, Leigh described that when ‘***Dad***’ sought ES-CSS from the headmaster following a bullying incident, that this wasn’t given. Leigh expressed relief when his ‘***Dad***’ intervened and talked to the ‘bully’s’ mother about her child’s bullying and how it then stopped.

4.7.4 Procedural steps 1-2: Secondary CTT

4.7.4.1 Emotional-social transitioning concurrent stressors (EST-CS)

Prior to starting secondary school, Leigh shared his EST-CS at this time as, ‘**being forced to have a shower during P.E.**’ (physical education), which he later found out was not compulsory.

> “*Scared about? I’m not sure there was masses that I was scared about I’d say. I mean I was a little concerned that we’d have to have showers in P.E. As it turned out they weren’t compulsory*”.(P204/00:31:45)

4.7.4.2 The major concurrent stressor ‘being undiagnosed ASC’ (Un-CS)

The first-time Mum heard the word ‘autism’ mentioned in relation to Leigh and his difficulties was in secondary school, when a special needs teacher identified Leigh had difficulties, which needed to be understood. Mum stated that the teacher encouraged them to pursue a diagnosis so that Leigh would be eligible for the extra time needed in exams. Mum said, “*I think Leigh was 14* (when he had his official autism diagnosis)”.(PFM204/00:09:27) Leigh shared that when Mum told him he had ‘Asperger’s’ (autism) he had a combination of feelings, particularly worry about autism being potentially serious and relief that he now had an explanation for some of his difficulties and differences.

> “*Well, I think my initial question I asked was, ‘Is it serious?’ because I think when you’re a child and you’re told that you have a syndrome, you then begin to think, ‘Is it a problem?’ And then my mum...*(pause)*...because it was mum who told me. She explained what it was, what it meant, and I think a lot of things suddenly made sense from the why I’d had...*(pause)*...because at that time at school I had a fair few difficulty and the reason behind that became very clear*”.(P204/00:02:14)

Leigh investigated what ‘Asperger’s’ was and his face lit up as he described how having a few “*random*” key interests was a feature that he shared with others on the autism spectrum.

> “*I did some background research on it, on Asperger*’*s... I looked on the internet... It did* (make sense) *because it talks about...*(pause)*...one of the major things for me was having only a few key interests and how they can be very...*(pause)*...sometimes they can be very random things … how some people can have interest in things like molecular structure, very specialised areas and of course for me my specialist area was natural history so it was kind of a blessing really because that at least is an area where that has several occupations tied to it*”.(P204/00:03:38)

4.7.4.3 Academic concurrent stressors (Ac-CS)

When Leigh arrived at his secondary school he recalled being, “*…very impressed especially by the science labs because they had all those specimens in jars and whatnot, and yeah, I think they had a couple of organs I think from a pig that they would let you put on these gloves and feel*”.(P204/00:29:32) He stated how English literature became his favourite subject, which he excelled at in secondary school.

> “*English, that became better for me. Yeah, it got better … I mean the subjects were broader and later on we*’*d do a bit of poetry …and I think the big break in English for me was when we ...*(pause)*...We did* ‘*To Kill a Mockingbird*’ *which I loved and still love. It was really a good experience and it*’*s where I sort of began to get properly interested in writing and putting my creativeness down on paper especially later on a bit… struggled a little bit at first but later on it flowed*”.(P204/00:36:09)

In general, Leigh described his Ac-CS ‘**having to learn about topics he was not interested in**’, which appeared to challenge him during this CTT.

> “*Well, I suppose it was* (challenging) *dealing with all the subjects or aspects of a broader subject that I was less interested in*”.(P204/01:30:49)

Leigh described, ‘**math**’ CS as “*slightly better*”.(P204/00:39:20)

Ac-CSS

Thus, ‘***reasonable adjustment***’ Ac-CSS was provided to Leigh by his secondary school. He was entitled to this for his GCSE exams in the form of an ‘***additional 25% extra time***’, and ‘***use of a laptop***’.

Leigh expressed that the reason he did so well in some of his subjects in secondary school was due to the Ac-CSS he received from his ‘***supportive teachers***’, particularly from his ‘***math teacher***’.

> “*…The* (math) *teacher … actually helped me with the homework because we did a lot of those were on the special site specifically for…like an intranet, that we do our homework on that and she would come with me to the library at lunch times. I mean I had other subjects which I had to do at home, but at least the math was one less thing to do. and we’d do it then*”.(P204/00:39:20)

He described his ‘***history teacher***’ Ac-CSS as ‘brilliant’ based on this teacher’s; energetic style, passion, and detailed understanding about the topics he taught, how he treated Leigh as an equal, used jargon free language, and was approachable.

> “*Academically I think I did better. The main difference was the teachers. With only one or two exceptions, they were all extremely supportive… History was a big one. My history teacher Mr.* ‘D’ *... he was brilliant. I think he’s still teaching... he was very good at the subject that he taught. He was clearly passionate about it. He always taught in a way that was easy to understand*”.(P204/00:33:37)

> “*Umm…well…he never talked down to us, he always put a lot of energy into his lessons, he never used* ‘*jargon*’ *… or anything…it was always a language that was easy to understand…history doesn’t tend to have masses of jargon in it compared to say science or math but still it was always in a format that was easy to learn … He was always very approachable…*”(P204 int·2/12·26)

Leigh described the teaching style of his '***Religious Education (R.E.) teacher***' as,

> "*fun… R.E. was always fun. Mr* 'B'*… our R.E. teacher, he was a really interesting person. He always encouraged us to ponder as he would say … because it was fairly broad because we looked at not just various religions, but it was also the one where we were told about things like drugs, alcohol* ...(pause)...*sex and all that jazz*".(P204/00:35:06)

4.7.4.4 Emotional-social concurrent stressors (ES-CS)

Leigh described ES-CS due to '**being bullied**' during this CTT, using passive, despondent, withdrawn, communication. He made a statement about not having a "*backbone*", likely reflecting ES-CS, resulting from '**feelings of shame that he was not able to stand up for himself**'.

> "*I'm not a confrontational person by nature ... Certainly, I wasn't at that time. I didn't have a lot of backbone*".(P204 int-2/00:20:20)

He described '**being dismissed by his peers**' CS and '**being shouted at by his peers**' CS.

> "*...at secondary school I was a complete fish out of water and most of the...*(pause)*...especially the other boys would have nothing to do with me... I think because a lot of them came from farming communities so they're quite, kind of polar opposites. So, every time I try to speak my mind I just get either I guess get dismissed…out of hand or else shouted down. So, I didn't really like school that much*".(P204/00:49:27)

Continuing he described '**feeling different to his peers**' CS, '**being ignored by his peers**' CS and '**being told to shut up by his peers**' CS.

> " *I guess at first it* (secondary school) *wasn't so bad because well we were all strangers and we hadn't yet figured out* '*who was who*'*, but for pretty much all my secondary years that was the toughest part for me. I think I only had I think*

> *one person who I could at least interact with without either being ignored or just told to shut up*".(P204/00:41:17)

Emotionally Leigh stated he experienced, '**feeling downtrodden**' CS.

> "*...downtrodden to be honest ... Well... Well, I think it was partly because I was the only one at school that seemed to have any interest in my subject area* (conservation and the environment)".(P204/00:48:56)

This was sadly acknowledged by Mum, who also shared that she believed Leigh experienced ES-CS because of '**peers who did not want to learn in class**'. Although Leigh felt "*downtrodden*" in secondary school he was still reasonably positive about his school in general stating, "*...um yea...it was a grind...but it wasn't hell*".(P204 int·2/00·20:57)

When Leigh was asked how he got on socially in secondary school he shared that he didn't like going to school, that it was his toughest social experience, summing this up with a sad tone, and one sentence "*that was the biggie!*" and "*...my difficulties in socialising didn't help at secondary school. That's why that was probably the toughest for me socially*".(P204/01:31:57) Leigh described ES-CS due to '**social difficulties with peers**', how he would avoid social contact during secondary school hours, intentionally spending time alone reading in either the library or in his form room.

> "*Mostly just keeping to myself. I'd go...*(pause)*...well to the library and read or else go to the form room and read there, generally just keep to myself*".(P204/00:44:49)

ES-CSS

Leigh continued to receive ongoing ES-CSS from his '***Mum***', '***Dad'***, who were, "... *very supportive*",(P204/00:30:59) '***best friend*** '***S***'' and '***his books***'.

Even though Leigh experienced, '**being bullied**' CS during secondary school he referred to the ES-CSS from his '***supportive teachers***', as his "*...saving grace ...they were the ones who were really supportive*".(P204/00:49:27)

Socialising in secondary school was tough for Leigh however he did share that he had ES-CSS from another '***best friend*** '***W***''.

> "*...I think I only had I think one person who I could at least interact with without either being ignored or just told to shut up … His name was* 'W' *… and I only knew about him because I guess I had met him beforehand because he lived a bit further away and to save a small bit of a journey, he would drive to us and then my dad would take the both of us toward the school*".(P204/00:41:17)

Not accepting ES-CSS

There were clearly periods in Leigh's secondary CTT when he needed ES-CSS (and Ac-CSS), but didn't want it, as clarified by Mum.

> "(He)*… didn't like the idea of anything being stirred up or any...*(pause)*...he doesn't like conflict...and so making trouble, he didn't want to make any trouble… He doesn't respond well to being questioned about things; he doesn't like, you know … he's not forthcoming with conversation…I think part of this strategy for coping with school was not really sharing much about it outside with us actually, and I think he didn't want us interfering, um...*(pause)*...you know, going along saying, 'Our son can't study because someone's…'…*".(PFM204/00:57:23)

4.7.5 Procedural steps 1-2: Sixth form CTT

4.7.5.1 Academic concurrent stressors (Ac-CS)

Starting sixth form, Leigh explained that he experienced Ac-CS due to '**the jump from GCSE biology to A-level biology**'. Finding this academic leap too big resulted in him deciding to switch to a BTEC in the second year of this CTT and him ending up taking three years to complete this CTT instead of two.

> "*Biology I struggled with a fair bit because it was kind of too big a jump for me to get my head around… So, at my second year I dropped philosophy and switched from biology to BTEC science and did two years' worth of that and that I found better, because it was spread across… a slightly broader spectrum than biology had and also, well the second year a lot of BTEC I enjoyed because that was looking at forensics*".(P204/00:53:04)

'**A-level exams**' CS meant that Leigh didn't quite get the results that he needed to study the DICE (Durrell Institute for Conservation and Ecology) undergraduate course. However, 'the chosen' University decided to accept him based on his BTEC distinction in biology (to be discussed further in the university (BSc) CTT section 4.7.6.2).
'**Running out of time even with 25% extra time being given**' continued as a CS throughout this CTT.

Ac-CSS (Evidence of good support practice)
Sixth form '***reasonable adjustments***' CSS was provided in the form of: '***additional 25% extra time in exams***', and '***use of a laptop***'.

4.7.5.2 Emotional-social concurrent stressors (ES-CS)

Leigh stated that he was less reactive to taunts, and how he felt this resulted in peers realizing that he had "*toughened up*". (P204 int-2/00:27:56) He described how he was now able to stand up for himself, with the presenting appearance of shame, which he previously demonstrated discussing secondary school experiences, being replaced with a presenting appearance of pride.

> “ *It* (sixth form) *got a bit better. Socially speaking that was*...(pause)...*yeah ... Both of us have matured by then and I began to find it easier to interact with them. Because it was two-year groups in the sixth form and the one above us, they were all really great people. Yeah, we got to properly interact with them. Yeah, it was fun. The best years of my secondary school were definitely the sixth form years*”.(P204/00:51:23)

> “*...Yeah…Well, I think it was because we’d moved to the stage in year two* (aged 17/18 years) *where you start to calm down ... I think as you really start to reach the end of your teens, the fog starts to clear, and you start to take a serious look at yourself and….And it’s the time that I decided to pull myself together as well ... Well, I wasn’t as quick to get upset as I had been ... Well, taunts or… anything, anything slung at me ... There’s one quote by Tyrion Lannister, ‘Show them their words can cut you and you’ll never be free of their mockery’. Well, they didn’t do it as much anymore. And I think when they’d realised that I’d toughened up a bit, they stopped being as malignant. I think that’s the word...Malicious. Yeah, that’s…I think that’s it*”. (P204 int-2/00:27:56)

ES-CSS (Evidence of good support practice)
Leigh continued to receive ongoing ES-CSS from his ‘***mum***’, ‘***dad***’, and ‘***his books***’. ‘***supportive teachers***’ and ‘***head of sixth form***’ which appeared to provide ES-CSS (and Ac-CSS) to Leigh throughout this CTT and particularly with his transition into university (see section 4.7.6.1).

4.7.6 Procedural steps 1-2: University (BSc) CTT

4.7.6.1 Emotional-social transitioning concurrent stressors (EST-CS)

The only worry that Leigh mentioned having prior to transitioning into university was that he might still experience, '**social difficulties with peers**' CS, and that he would find it hard "*fitting in*", however this was in fact "*groundless*".

> "*What worried me? Well, I suppose there was some concern initially that I might have difficulty fitting in but as it turned out, no, that fear was groundless*".(P204/01:09:28)

Leigh, when asked how he prepared for university, focused his answer on academic preparation, not mentioning the independent living elements.

> "*How did I prepare? ...*(pause)*...I suppose envisioning what experiences would be like, think about the subject, lectures, and such…And I had a look at the modules that they took up because we had to choose them as well. Yeah, I did a bit of background on some of the lecturers and their subject areas. That I suppose is the main way I prepared. I mean socially I just took it as it went*".(P204/01:19:21)

Living independently during Leigh's first year ran smoothly for him, meals were catered for which meant that he did not need to cook for himself.

> "*Well, we had suppers on campus. My first year on campus that was probably the easiest. I mean I just did my own breakfast, maybe a sandwich at lunch or else the venues on campus... It was pretty good, better than the average school dinner I'd have to say*".(P204/01:20:53)

EST-CSS (Evidence of good support practice)

Leigh detailed that he received EST-CSS from his '***head of sixth form***' who '***assisted him in his university application***', his '***personal statement***' and setting up his '***reasonable adjustments***' with the disability department at the university.

> "*...we had some assistance with those* (application to uni). *Yeah, I think it was the head of the sixth form who would look over the statements, give us feedback … I think someone at my … school made contact. They would send a letter as confirmation and we then got in touch with the disability support group at the uni. and they received that, so I got my extra time and such and I went to visit at least once every year*".(P204/01:00:34)

Leigh, when asked about the EST-CSS he received from his '***sixth form teachers***' during his transition into university, said that some of his teachers positively ensured that he had '***good revision notes to take with him***' and influenced his choice of university subject (due to the way they had delivered their subjects).

> "*...certainly, my geography and history teachers, well they were both very good at the certain subjects they taught, how to make it very interesting. I did quite a few of my revision notes*".(P204/00:56:07)

Leigh based his choice of university on the connection and CSS he had from '***the Durrell Wildlife trust***' and was excited to be focusing on his specialist interest by taking the DICE course.

'***Mum***' and '***Dad***' EST-CSS continued for Leigh during his visits to universities with, "*...a couple of trips to other universities...* 'the chosen university' *… it was a bit far away. We did other ones at* 'C' *and to* 'B'*…*".(P204/00:58:33) When Leigh visited 'the chosen' university he received EST-CSS from his '***good friend*** '***D***'', a friend who was already at 'the chosen' university, whom he met up with.

> "*… my good friend* 'D'*… So yeah, I actually went down to visit the uni. while he was still there … and got to meet some of his colleagues and yeah, I had a look around the uni. and one time when I went to Jersey Zoo I met some...*(pause)*...because the people who the course have a trip to Durrell, to Jersey Zoo and go behind the scenes and I attended that... I think it was through invitation from Lee Durrell who invited me to have a look, look around*".(P204/00:58:33)

4.7.6.2 Academic concurrent stressors (Ac-CS)

A-level exam results meant that Leigh didn’t quite get the results that he needed to study the DICE course, resulting in initially a continuation of ‘**A-level exam**’ CS, however, his chosen university decided to accept him based on his BTEC distinction in biology instead.

> “*... I already knew which university course I wanted to take which was the DICE course down at* ‘the chosen university’ *... Durrell Institute for Conservation and Ecology, it was a course on wildlife conservation ... I didn’t quite manage to get the grades required for geography and history. You needed a B in each. I ended up with a D in geography and a C in history ... But I managed to get a distinction in BTEC science so.... So yeah and that I think is what got me my place at* ‘the chosen university’…”.(P204/00:54:07)

Leigh happily described university as a positive opportunity where he could focus entirely on his subject of interest.

> “*The biggest one for me was probably actually only doing, focusing on a subject that I was entirely interested in*”.(P204/01:09:15)

He was proud to be taught by experts in the field.

> “*What was different? Well, I suppose well we were being taught by real experts in their field. Some of them have been to various parts of the world, been directly involved with conservation*”. (P204/01:04:12)

He described a change in the learning style from sixth form to university education, which now focused more on him being an independent learner, explaining that being an independent learner as well as being able to focus on his subjects of interest, suited him well as these were his academic strengths.

> “*...the assignments it was now onto essay questions, so slightly tougher, but on the whole, it was mostly on subjects that I was interested in and I found it a lot easier. Now we have a couple of weeks to do each of our assignments. Well, it was more of the self-taught thing ...which kind of suited me if you will*”.(P204/01:03:21)

Leigh mentioned experiencing Ac-CS due to ‘**leaving work to last minute**’ and ‘**his computer crashing**’.

> “*Well, I confess I had a tendency to leave things a bit late …like… because to be honest I found the work a bit better with a time crunch, although I remember at least one point during my second year this nearly proved my undoing because … It was a 2,000-word essay …I’ve been working on it for the past few days, and this was the day before it was a due and I only had a little bit left and for some reason I tried to open the document and it just wouldn’t open. It just … it just crashed. So, I had a minor breakdown then but got it together and just sat there and typed it all over again from memory … It was a subject I was interested in which was a major plus, but I was so afraid of losing it again that I didn’t leave the computer until I’ve got it finished. I didn’t even stop to go to the loo. I just stayed in front of machine as it was done. It took five hours solid work which I guess isn’t too bad though. I did need a drink afterwards when I got home, but I got it finished on time and I got a good mark for it*”.(P204/01:06:38)

Ac-CSS (Evidence of good support practice)

Leigh shared that he received Ac-CSS from his ‘***lecturers***’ with the ‘***academic department***’ in the university, that they gave him ‘***clear instructions about assignments***’, ‘***revision materials***’, ‘***access to an intranet***’, ‘***an open-door drop in policy with lecturers***’, as well as ‘***an academic tutor who would answer any questions he had***’.

> “*...they’re* (the academic department/lecturers) *always very clear in terms of assignments. We’d be given a revision material. I think maybe go on our intranet for us to look through but have revision sessions. We’d always be welcome to go and question them if we had any queries … We had tutors who we went and spoke to … I’d sometimes go to go to lecturers if I had problems with certain assignments, any questions about them*”.(P204/01:24:34)

The ‘***disability team***’ ensured that Leigh had ‘***reasonable adjustments***’ Ac-CSS which took the form of ‘***additional 25% extra time in exams***’ and ‘***use of a laptop***’.

4.7.6.3 Emotional-social concurrent stressors (ES-CS)

Leigh happily explained that by the time he reached university socialising didn't cause him as much difficulty as it used to. Although he highlighted that there were occasional moments of conversational lapses, and he disliked crowded night clubs, but nothing major that limited his ability to socially interact.

> "*Well socially wasn't such a problem there anymore although there were occasional moments when I felt like I'd gradually drifted out of the conversation, but I generally managed to get back into things. I mean I wasn't a massive drinker at the time though I would drink to be sociable … Biggest challenge*...(pause). *Much more of it is there wasn't really any major social challenges* ...(pause). *That being said I mean I don't like being in a confined space with too many people and I guess the clubs could get fairly congested sometimes*".(P204/01:16:29)

His face lit up and there was joy in his voice as he described all the "*amazing people*" he met at university, particularly through various societies he joined.

> "*Socially, a massive improvement especially with the various societies… I think the first one I joined was the Conservation Society. That was a big one. What else? Let's see. There were a few joke ones like The Pirate Society which was … They'd just dress up as pirates all together now and they'll watch pirate films. They also had various events that would raise money for the RNLI … The Conversation Society was a big one for my first year and the second year as well. And also, second year I was introduced to creative writing who proved to be major ones and they were... really good friends*".(P204/01:01:57)

Leigh's emotional well-being appeared to improve due to being surrounded by mature, sensible and compassionate people.

> "*Well, it's just been really refreshing to be in this environment with so many people who are far more mature, sensible, and passionate. That's one thing that seemed pretty lacking at school. There was a lack of passion. Not among the teachers, they were all very passionate but among the students. And so many of the young people I met at uni just oozed passion and compassion … I supposed*

> *its been really satisfying to meet people like that and just to know that there are these people out there*”.(P204/01:36:42)

He went on to described how he felt he flourished during this CTT and how his morale, in terms of social interactions, grew.

> “*Well, I’d hoped it would be an environment that I could probably flourish in but I obviously didn’t know how many amazing people I’d meet, just how much... much it would be that boost to my morale*”.(P204/01:13:20)

At university additional Ac-CSS and ES-CSS was made available to Leigh in the form of ‘Disabled Student Allowance’ (DSA), although entitled to this, he stated that he felt his condition wasn’t serious enough to warrant applying for it.

> “*Well, the disability allowance certainly I knew what that were for ... It felt like my condition wasn’t serious enough to require all of those ... I mean I did consider it, but I decided that what I had already would suffice*”.(P204/01:12:36)

> “*I decided not to because I didn’t…that’s partly because I didn’t feel it was intense enough to fully warrant it*”.(P204 int-2/00:31:47)

Mum sheds some light on the likely reason as to why Leigh decided not to apply for DSA, due to ‘**a phobia of filling out forms**’ CS.

> “*Well, we did talk about the DSA, and he said, “I don’t think I need to go for DSA” I mean we did get all the information about that and we did...*(pause)*...but I think the horrors, the forms probably freaked him out so much … You know, to get any sort of help or any money from anywhere is such a challenge to someone who doesn’t like paperwork and forms that he would rather go without than go through all that...*(pause)*...you know, I mean we had...*(pause)*...every year that would be...*(pause)*...with the student finance and things like that if… Well, its...*(pause)*...and I think it makes Leigh nervous because he’s terrified of doing things wrong, I think that is the...*(pause)*...he sees that as authority, and he doesn’t want to challenge authority*”.(PFM204/01:58:11)

‘**Anxiety about world affairs**’ CS appeared to escalate during Leighs’ university (BSc) CTT leading on to ‘**a phobia about world news**’ CS which resulted in him avoiding watching, discussing, world events. These feelings were something that he didn't want to discuss with others, resulting in extreme avoidant behaviour and thoughts, feelings, which he kept to himself.

> "*Emotionally, well I think that was the time when my anxiety over the news began to kick in … Well, I think it just started in 2012, because there was all that nonsense in the papers about 2012. Everyone thought the world was going to end and whatnot. That's when I started to really avoid it. … then it changed to sort of more realistic concerns like world relationships, North Korea, those more pressing issues and the tensions and I just didn't want any of that...Well I confess generally I just keep them bottled up. The things like world affairs, I just didn't want to discuss full stop… the only news I do probably look at is … BBC Wildlife that looks at news in conservation and climate change. That I keep up to date with. Everything else though I tend to avoid even now*".(P204/01:17:59)

Such phobia's and related symptoms strongly indicated the likelihood that Leigh had CS because of '**undiagnosed OCD**' (obsessive compulsive disorder), as shared by him.

> "*Well, I'm pretty sure I have OCD, in terms of compulsiveness because I'll often find myself …*(pause)*… things like locking a door or making sure I've shut the fridge or turn off a tap, often I'll check those, go back to check a lot of times even though I've done it once already or like I'm thinking, "Wait, am I absolutely certain?" and go back and check again. I think the locking doors is the biggest issue because of the …*(pause)*… well I guess the security factor there is a big one for me*".(P204/00:04:36)

During Leigh's second and third years an emotionally significant negative episode occurred, when he moved into a student house off campus, resulting in '**having to take on the responsibility of paying the household bills**' CS and '**a phobia of paying bills**' CS.

> "*Second and third year I moved into a place in town. Those are slightly tougher. The second year was with someone on my course so that was something I had a bit of additional support, but I was the only one who stayed on the place for the third year so I just met a bunch of new people and certainly a couple of them are from fairly privileged background is not used to doing things so that was where*

> *I kind of had to shoulder a lot of responsibilities like the electricity, the water bills and the internet as well*".(P204/01:21:06)

His dad elaborated on these CS stating that, "…*he* (Leigh) *paid their bills in the end and you know, because they wouldn*'*t give him any money, it was dreadful*".(PFD204/01:41:38) As hard as this experience was for Leigh, shouldering the responsibility of paying bills, he still proudly stated that this experience was his greatest achievement in terms of gaining independent living experience.

> "*Getting a taste for independent life, dealing with the bills, those and whatnot, basically well, having to* [inaudible 01:37:22] *and I guess as troubling as it could be at times certainly my third year when I had to shoulder a lot of responsibilities it at least gave me experience*".(P204/01:37:09)

Returning home after completing his degree Mum and Dad were concerned about Leigh's emotional well-being, and his overwhelming phobias in the form of '**a phobia of filling out forms**' CS and '**a phobia of paying bills**' CS. Mum stated that, "...*he came back in quite a state … and he freaks out with forms, he got freaked out when he got a thing from the student loan, wanting to know his status with regard to you know, employment and he doesn*'*t cope well with all of that stuff*".(PFM204/01:42:52)

ES-CSS (Evidence of good support practice)

Leigh shared how he was "*much happier*" during his university years, and experienced ES-CSS from his '***good friend*** '***D***'' and '***fellow students***'. He continued that they supported each other emotionally.

> "*I guess a lot of the students we gave a fair amount of emotional and physical support to each other*".(P204/01:25:16)

> "*I was much happier...I was finally among people who I could actually talk with and interact with. It was people who knew about the subjects I were interested in. Lots of really fun, mature people well from all over the world. It*'*s a very multicultural uni and I loved that. I really liked being surrounded by so many wonderful people*".(P204/01:08:19)

Leigh received regular ES-CSS from ‘***mum***’ and ‘***dad***’, who he was, “…*always in contact so that wasn*’*t an issue … About once a week*”,(P204/01:25:16) as well as continued support from ‘***his books***’.

Did not accept additional ES-CSS (Ac-CSS)

Leigh chose not to accept additional ES-CSS (and Ac-CSS) through DSA (Disabled Student Allowance) as he felt his condition was not serious enough to warrant this support, although a phobia filling out forms what also evidenced as another possible contributing factor.

4.7.7 Procedural steps 1-2: University (MSc) CTT

4.7.7.1 Academic concurrent stressors (Ac-CS)

Leigh described his MSc assignments as resulting in '**the most challenging assignments he had ever done academically**', especially when they involved '**statistical analysis**'.

> "*Well, my postgrad* assignments *have been the most challenging from an academic perspective. Well not all of them but some of them have been really, really difficult because it was a* massive *step-up from my undergrad*".(P204/01:03:21)

> "*...some of the things that were required for that area of work I mean…*(pause)*…it wasn't specifically wildlife conservation, my postgrad. It was environmental biology looking at conservation and the management of resources, relevant but slightly broader and a lot more intense, ...and some things that are required in that field of view are the ones that we had to do assignments about, things like I think like the Darwin initiative or all the planning that's required for major conservation projects. It was so tough and using r for stats that was really, really tricky*".(P204/01:28:58)

Ac-CSS (Evidence of good support practice)

Due to these challenges, Leigh made the conscious decision to use the Ac-CSS provided by the university's '***Disability/ASC service***', who set up his '***reasonable adjustments***' for exams, which were, '***extra time***' and '***use of a laptop***'.

4.7.7.2 Emotional-social concurrent stressors (ES-CS)

Having '**a phobia about world news**' and an '**anxiety about world affairs**', appeared to continue throughout Leigh's MSc CTT, still ongoing at the point at which the research interviews took place.

> "*Well, the only news I do probably look at is the one at again BBC Wildlife that looks at news in conservation and climate change. That I keep up to date with. Everything else though I tend to avoid even now*".(P204/01:18:15)

He continued to experience '**worrying about others**' CS, especially worrying about his parents safety.

> "*I mean I know the things I'd worry about later, were things like when my mum and my dad went off somewhere and I was worried there might be an accident or something*".(P204/00:24:30)

Mum and dad confirmed that Leigh continued to have '**a phobia of filling out forms**' CS and '**a phobia of paying bills**' CS, during the MSc CTT, and that these phobias were also ongoing at the point of the interview.

> "*…such a challenge to someone who doesn't like paperwork and forms that he would rather go without than go through all that, you know… I think it makes* 'Leigh' *nervous because he's terrified of doing things wrong, I think that is the… he sees that as authority and he doesn't want to challenge authority*"(PFM204/01:57:18)

ES-CSS (Evidence of good support practice)

Whilst studying his MSc Leigh shared that he was involved with '***societies***' and in addition to these he also attended '***Eureka***' (autism social group) which provided him with ES-CSS.

> "*I'm pretty sure I try to make it to every Eureka group that I could*". (P204/01:44:32)

ES-CSS continued to be provided by '***Mum***', '***Dad***' and '***his books***'.

4.7.8 Procedural step 3

The categorical-form analysis (CFA) of Leigh’s data enabled me (the researcher) to gain in-depth insight into his linguistic dialogue, namely his tones of voice and non-verbal communication. This was performed by using Leigh’s fabula notes and tagging frequency of nonverbal (sjuzet) occurrences within his narrative statements, using reflective diary entries. CFA data was categorised into twenty-three varied tones, and non-verbals, and frequencies calculated. CFA data relating to Leigh’s state of health, positive and negative tones, and non-verbals (n=10), were then used to illustrate tonal frequencies within his narrative. Table 4.4 (c) details fabula notes and tagged positive and/or negative nonverbal calculation for each CTT, which will be discussed in more detail in next sections (appendix 4.4 (a) details a breakdown of these calculations).

Table 4.4 (c): The positive and negative linguistic tones and nonverbals used by Leigh during his interviews that were identified using the sjuzet data applied to statements made within the context of themes and subthemes.

		Percentage category occurrence of positive and negative linguistic tones/nonverbals in each CTT				
Tone or non-verbal used (frequency)	**Category (frequency)**	**Primary**	**Secondary**	**Sixth form**	**University (BSc)**	**University (MSc)**
happy (6) upbeat (6) pride (5) relief (3) joyous (2) gratitude (1)	**Positive** (20*)	20%	25%	20%	> positive 35%	n/a
sad (5) distressed (3) baffled (1) stressed (2)	**Negative** (9**)	22%	> negative 44%	11%	22%	n/a

*Positive (-3 tones (2 happy and 1 relief) did not relate specifically to a CTT and have been excluded) (Total n=6)
**Negative (-2 tones (1 distressed and 1 baffled) did not relate specifically to a CTT and has been excluded) (Total n=4)
NB: Not included in this table were factual and ‘other’ (emphasised, explanatory, contemplation, serious, determined, resignation, exasperation, sincere, hesitant, passive, despondent, shame) tones (Total n=13)
>Indicates the greatest frequency of tone type occurrence amongst all the CTTs.

4.7.9 Procedural step 4

Holistic-form analysis (HFA) combined HCA, CCA, CFA results, using the HFA scoring matrix (chapter 3, section 3.6.6.3, table 3.3), to produce an HFA numerical score that could then be attributed to a CTT (calculation shown in appendix 4.4 (b)). This score was then compared with another CTT to gauge Leigh's narrative progression or regression. HFA score also enabled consideration of the structure of Leigh's narrative, how he positioned himself within it, his typology, cohesion within his narrative and any turning points. The 'overall' core of Leigh's transitioning story showed a regressive, progressive, regressive, then stable narrative as he returned to a stable state of health (figure 4.4 (a)). The limitations of using a scoring matrix are discussed in section 6.7.

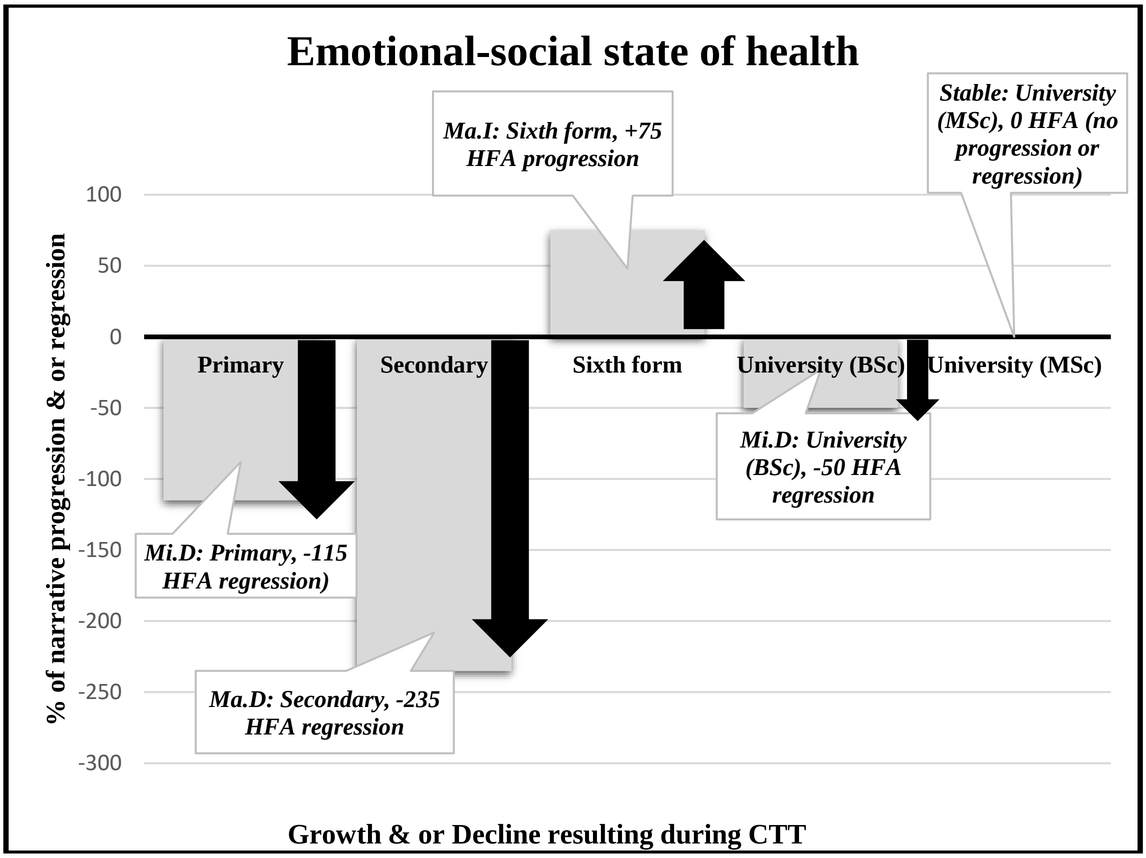


Figure 4.4 (a): Holistic-form: Narrative regression, progression, regression, stable state of health, of Leigh's Core Story, CTT, TST, in relation to state of health. MiD = Minor deterioration in state of health / MaD = Major deterioration in state of health / MiI = Minor improvement in state of health / MaI = Major improvement in state of health

The primary CTT demonstrated -115 HFA regressive narrative decline (figure 4.4 (a) column 1). Leigh's data indicated that he experienced a minor deterioration in state of health (MiD) during this CTT due to a minor increase in some ES-CS, '**being bullied**', '**being severely short-sighted**', '**loneliness**' and increasing '**social anxiety**'.

The secondary CTT demonstrated -235 HFA regressive narrative decline (figure 4.4 (a) column 2). This CTT had the greatest occurrence of CFA major negative tones discussing ES-CS experiences compared with other CTT (table 4.4 (c)). Thus, Leigh's data indicated that he experienced a major deterioration in state of health (MaD) during this CTT due to a major increase in ES-CS, '**feeling downtrodden**', increasing '**social difficulties**', and possible '**feelings of shame that he was not able to stand up for himself**'.

The sixth form demonstrated +75 HFA progressive narrative growth (figure 4.4 (a) column 3). Leigh's data indicated that he experienced a major improvement in his state of health (MaI) during this CTT due to no mention of new ongoing ES-CS, implying that he overcame previous CS or that these were considerably reduced. This CTT, appeared to be a major positive turning point for Leigh. This was likely to be due to the academic and emotional-social CSS resulting from having an autism diagnosis (aged 14 years).

The university (BSc) CTT demonstrated -50 HFA regressive narrative decline (figure 4.4 (a) column 4). This CTT had the greatest occurrence of CFA major positive tones discussing Ac-CS and ES-CS experiences compared with other CTT (table 4.4 (c)). However, Leigh's data indicated that he experienced a minor deterioration in state of health (MiD) during this CTT due to an incident in his final year resulting in ES-CS, and in addition to this OCD related symptoms and phobias.

The university (MSc) CTT demonstrated a zero HFA score, a stable narrative and state of health due to no change in ES-CS or new ES-CS (figure 4.4 (a) column 5).

4.7.9.1 Leigh’s Typology

HFA revealed Leigh’s typology throughout his narrative as a ‘hero’ typology. A narrative that portrayed how he courageously faced challenges with determination, overcoming these and achieving admirable successes both academically and emotionally-socially. Typology will be discussed in detail in step 6, section 4.7.11.

Table 4.4 (d): Calculation of Leigh’s Holistic-form analysis score combining HCA, CCA, CFA narrative data. HCA = holistic-content analysis, CCA = categorical-content analysis, CFA = categorical-form analysis, HFA = holistic-form analysis, CTT = core transitioning theme, CS = concurrent stressor, Ac = academic, ES = emotional-social, MiD = minor deterioration to state of health, MaD = major deterioration to state of health, MiI = minor improvement to state of health, MaI = major improvement to state of health

	Holistic-form analysis frequency and score									
	Primary		**Secondary**		**Sixth form**		**University (BSc)**		**University (MSc)**	
(i) Previously identified CS	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**
Major Ac-CS (impacting state of health) $^{(f \text{ x } -5)}$	f = 1	n = - 5	f = 1	n = - 5	f = 1	n = - 5	f = 1	n = - 5	-	-
Minor ES-CS $^{(f \text{ x } -5)}$	f = 6	n = - 30	f = 10	n = - 50	-	-	f = 5	n = -25	-	-
Major ES-CS $^{(f \text{ x } -10)}$	f = 3	n = - 30	f = 3	n = - 30	f = 2	n = - 20	f = 2	n = - 20	-	-
(ii) CFA linguistic (nonverbal) results	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**
Minor negative CFA $^{(f \text{ x } -25)}$	-	-	-	-	-	-	-	-	-	-
Major negative CFA $^{(f \text{ x } -50)}$	-	-	f = 1	n = - 50	-	-	-	-	-	-
Minor positive CFA $^{(f \text{ x } +25)}$	-	-	-	-	-	-	-	-	-	-
Major positive CFA $^{(f \text{ x } +50)}$	-	-	-	-	-	-	f = 1	n = 50	-	-
(iii) State of health	**Category (HFA total score)**		**Category (HFA total score)**		**Category (HFA total score)**		**Category (HFA total score)**		**Category (HFA total score)**	
MiD $^{(f \text{ x } -50)}$	n = - 50		-		-		n = - 50		-	
MaD $^{(f \text{ x } -100)}$	-		n = -100		-		-		-	
MiI $^{(f \text{ x } +50)}$	-		-		-		-		-	
MaI $^{(f \text{ x } +100)}$	-		-		n = +100		-		-	
	Total primary HFA score		**Total secondary HFA score**		**Total sixth form HFA score**		**Total university (BSc) HFA score**		**Total university (MSc) HFA score**	
	n = - 115 (regressive narrative decline)		n = - 235 (regressive narrative decline)		n = + 75 (progressive narrative growth)		n = - 50 (regressive narrative decline)		n = 0 (stable)	

4.7.10 Procedural step 5

To be able to illustrate to the reader Leigh’s ability to adapt to a CTT, I encompassed Leigh’s HCA, CCA, CFA, HFA data into the ‘educational transitioning model’, which visually detailed; (1) any CS that impacted his state of health, (2) ‘self’ characteristics, (3) concurrent stressor support (CSS) and (4) previous CTT state of health compared with current state of health. The educational transitioning models (figures 4.4 (b)-(f)) summarise Leigh’s lived experiences and educational journey in relation to his state of health.

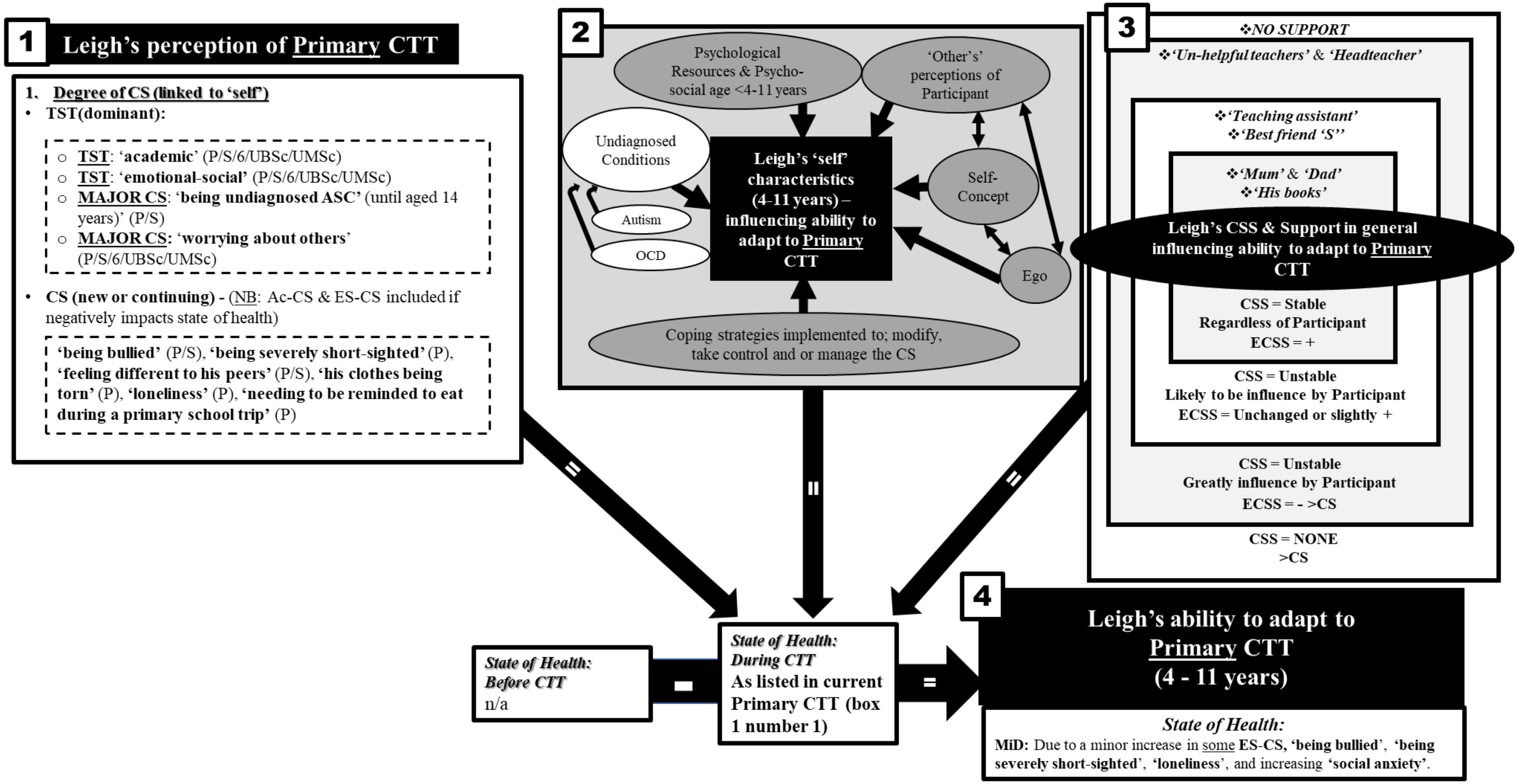


Figure 4.4 (b): Educational transitioning model representing Leigh's ability to adapt to the primary CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

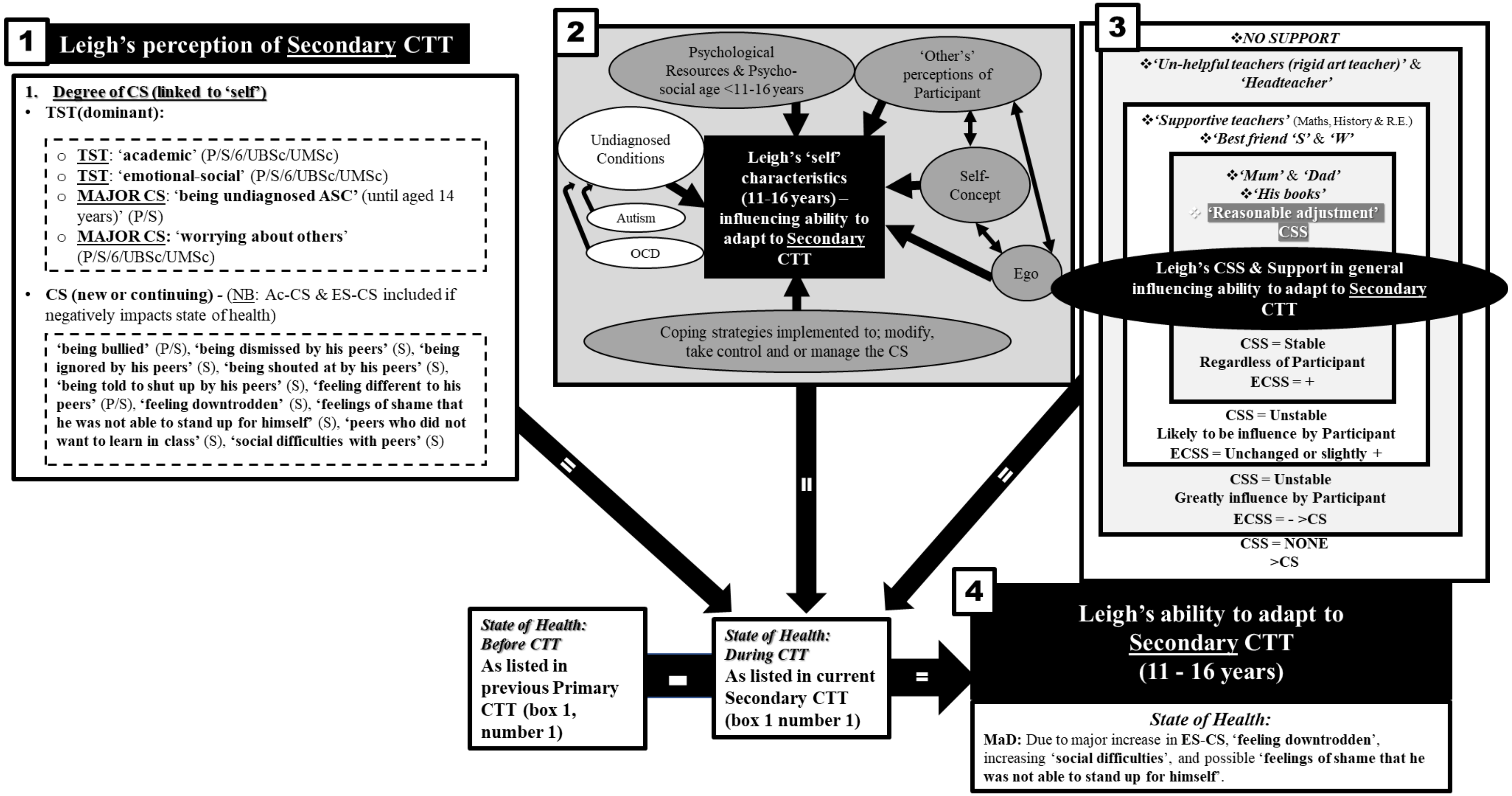


Figure 4.4 (c): Educational transitioning model representing Leigh's ability to adapt to the secondary CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268]

For abbreviations see chapter three, table 3.4.

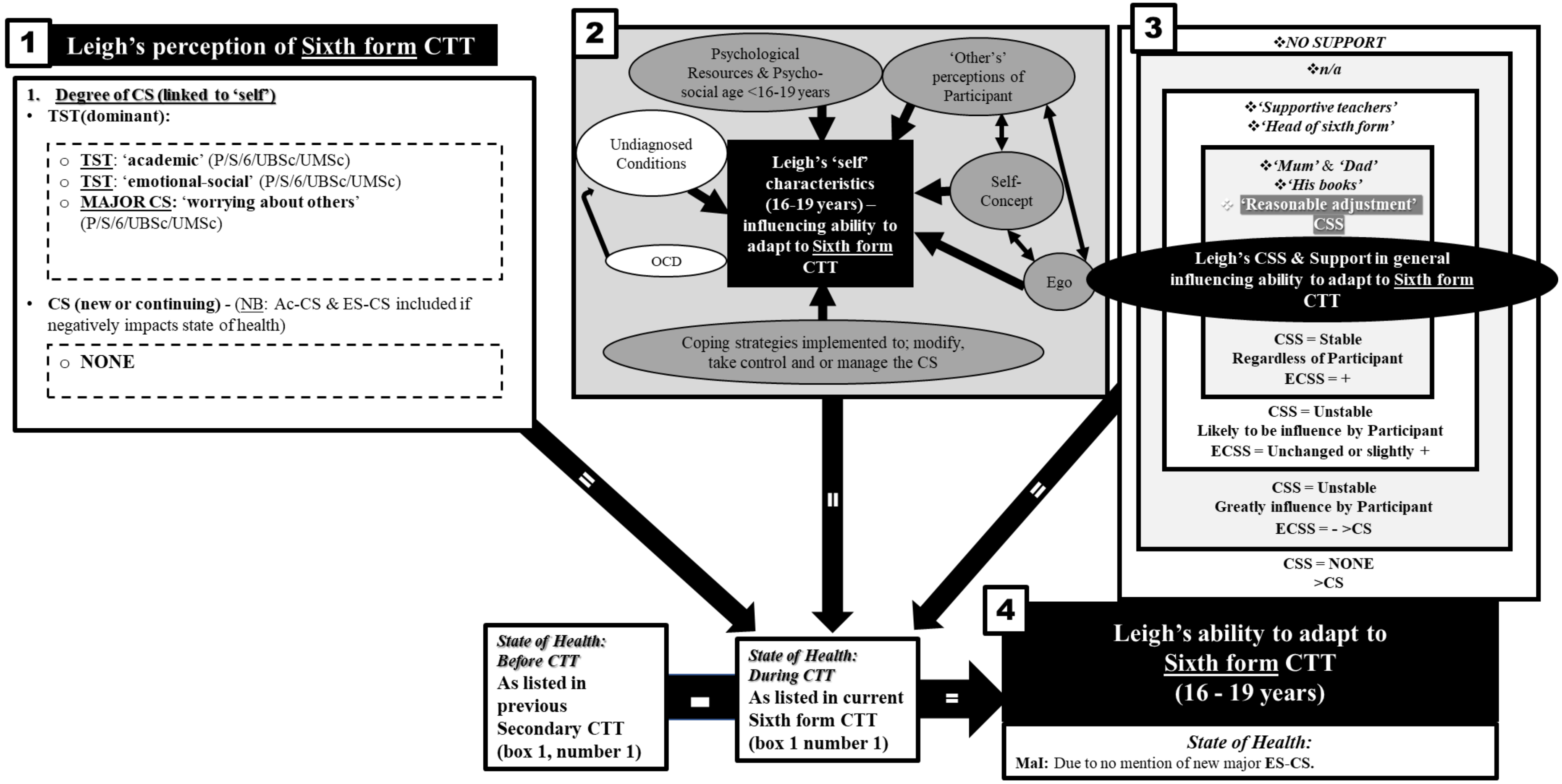


Figure 4.4 (d): Educational transitioning model representing Leigh's ability to adapt to the sixth form CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

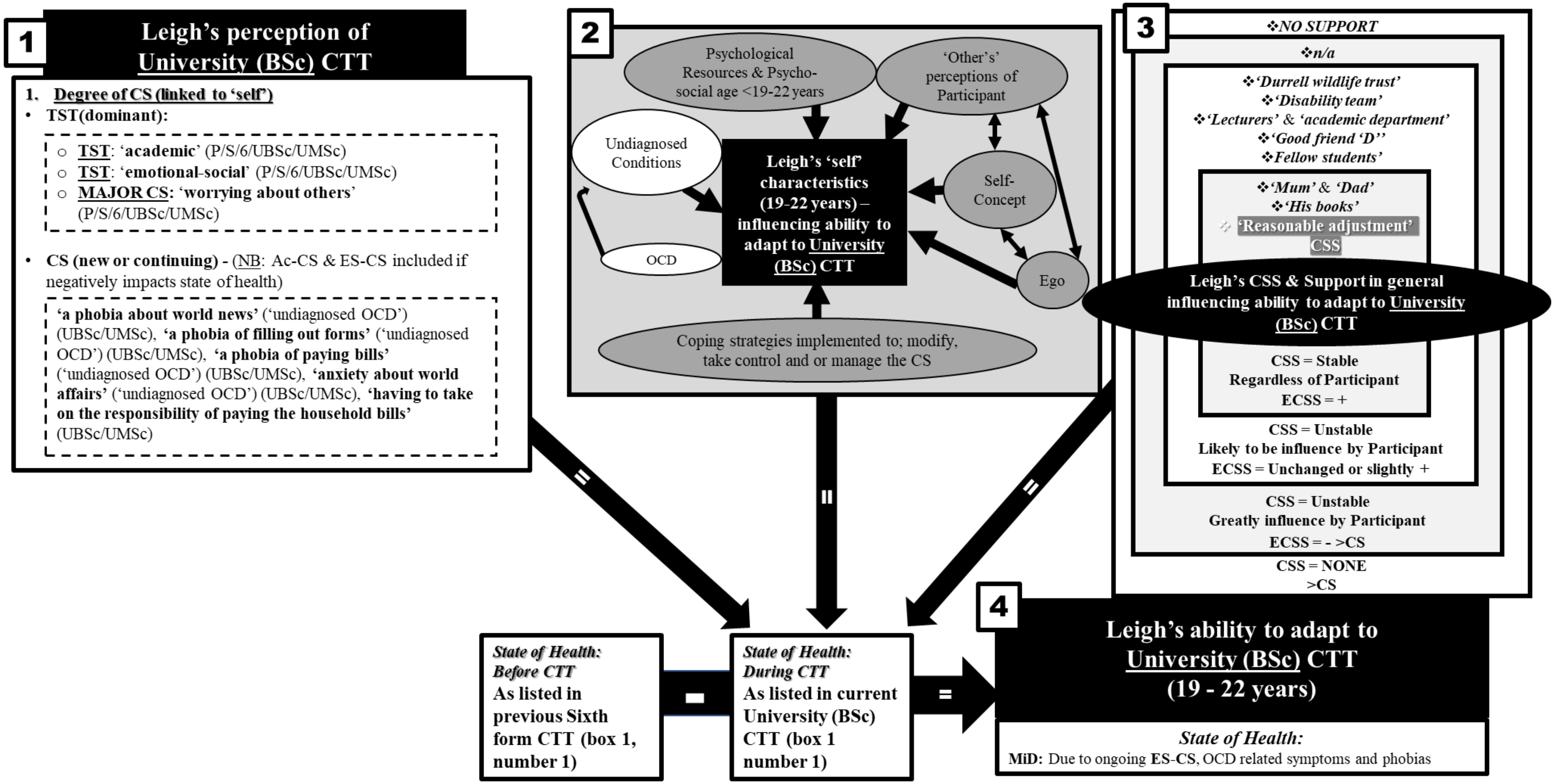


Figure 4.4 (e): Educational transitioning model representing Leigh's ability to adapt to the university (BSc) CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

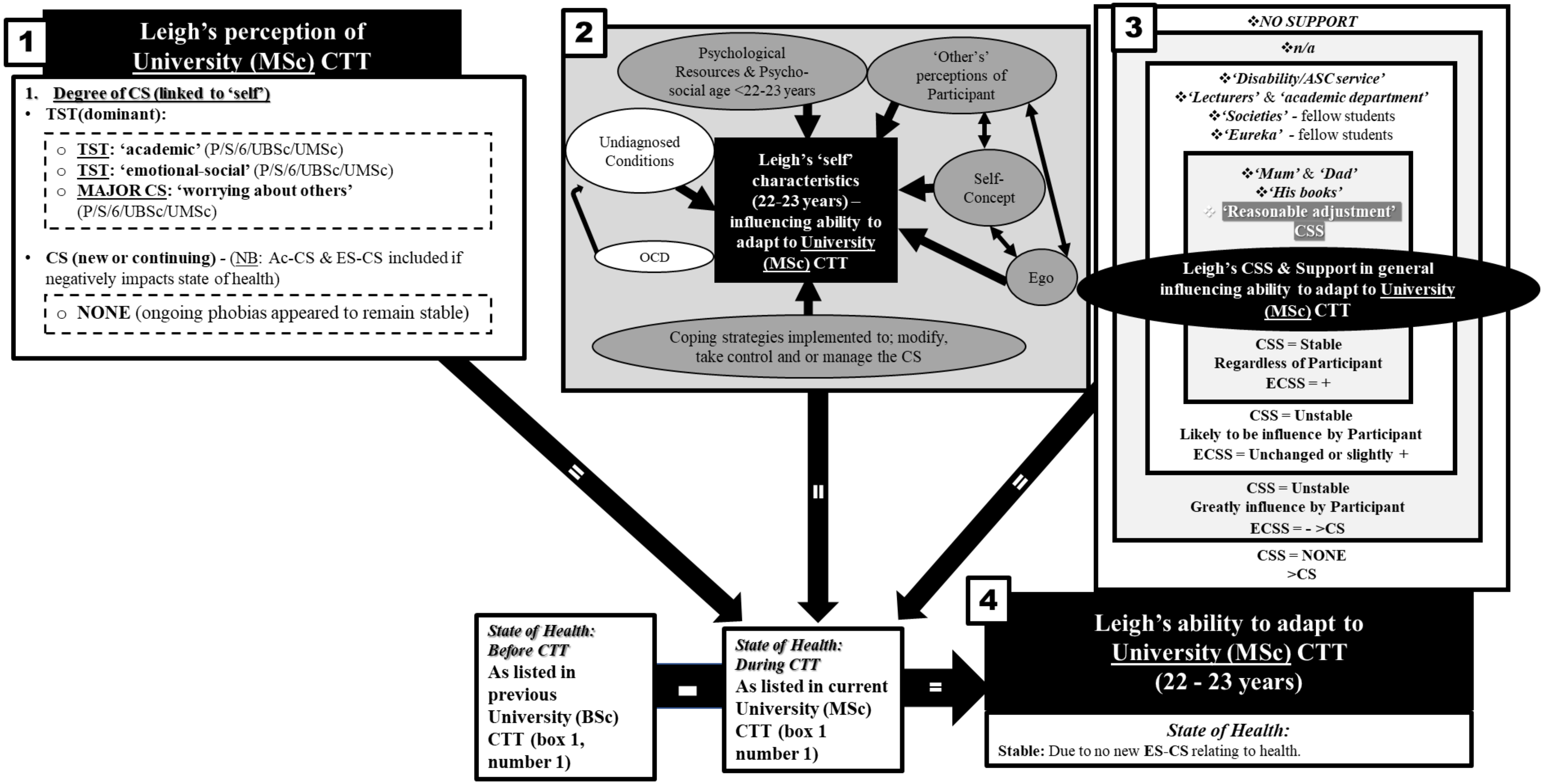


Figure 4.4 (f): Educational transitioning model representing Leigh's ability to adapt to the university (MSc) CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

4.7.11 Procedural step 6

Critical narrative analysis (CNA) considered the functionality of Leigh's story, how he was positioned within it, by considering the fabular and sjuzet properties reflecting his; thoughts, feelings, emotions, actions, interactions, achievements, challenges, and the social structure in which his story takes place. CNA identified a critical positioning theme; namely Leigh as 'The champion of wildlife and conservation' typology.

4.7.11.1 Leigh's positioning as 'The champion of wildlife and conservation'

Throughout Leigh's earlier years, prior to university, he positioned himself as being a '*fish out of water*', being different to his peers, often resulting in him being the victim of bullying, '*letting their words cut him*'. How Leigh positioned himself in relation to his peers, his reasoning as to why he was different to them, became clearer as his story progressed. During his secondary school years, he presented himself as 'The champion of wildlife and conservation'. Although, not demonstrated directly in the sjuzet elements expressed about his primary years, it should be noted that his positioning as 'The champion of wildlife and conservation' was demonstrated in the fabula elements of his primary school narrative when he described how he drew animal postcards that were then sold by the Durrell family in Jersey zoo.

The thoughts reflected by Leigh at secondary school were that he was the only one who cared about wildlife and conservation, which he felt was the reason other boys "*…would have nothing to do with…*" him. He reasoned that this was because they came from "*…farming communities…*", which he considered "*polar opposites*"(P204/00:49:27) to wildlife and conservation, and that this resulted in interaction difficulties with them. The tonal inference used to describe these thoughts expressed feelings and emotions of sadness. During his sixth form years Leigh continued to position himself as 'The champion of wildlife and conservation', applying and being successful in achieving a place at 'the chosen' university to study a BSc in the 'Durrell Institute for Conservation and Ecology', and then continuing at another university to do a MSc in 'Environmental Biology'.

Leigh experienced ES-CS due to being different to his peers, often unable to assert his position as the voice for ‘wildlife and conservation’, resulting in feelings that he was in the minority or even alone in this cause. Regardless of this, he demonstrated resilience and pride positioning himself as the champion of this cause throughout his story. Within his social structure, in terms of his peers, he portrayed himself as feeling ‘lesser than’ his peers, at least until he reached sixth form. However, in terms of wildlife and conservation, he portrayed himself as ‘greater than’ his peers, superior in terms of his specialist understanding and commitment to the cause.

Through determination, unconsciously in his early years and consciously in his later years, Leigh became ‘The champion of wildlife and conservation’ in his narrative. Resilience and improved self-advocacy skills enabled Leigh to face and overcome many challenges throughout, especially having differing views to his peers about ‘wildlife and conservation’ during his earlier educational years, which often resulted in bullying and social isolation. Leigh gained remarkable achievements in this area which resulted in him achieving his BSc and MSc in this field. Leigh clearly demonstrated that he achieved his lifelong goal as ‘The champion of wildlife and conservation’. Which he continues to do in this field, to educate and ‘enlighten other people’ about this cause.

4.7.12 Summary of Leigh’s ability to adapt to each core transitioning theme

HCA: CTT; primary, secondary, sixth form, university (BSc), university (MSc).

CCA: TST; academic (Ac), emotional-social (ES).

CFA: Greatest occurrence of major negative tones during secondary CTT. Greatest occurrence of major positive tones during university (BSc) CTT.

HFA: Indicated a regressive, progressive, regressive, stable narrative.

HFA & CNA: HFA linguistical analysis and CNA revealed a ‘hero’ typology throughout Leigh’s narrative which developed into ‘The champion of wildlife and conservation’ typology.

HCA, **CCA**, **CFA**, **HFA**, **combined (table 4.4 (d)):**

<u>Primary</u> CTT, evidences a regressive narrative. Evidence of good support practice took the form of: Stable CSS (regardless of behaviour) was provided by ‘***Mum***’, ‘***Dad***’ and ‘***his books***’, unstable positive CSS (influenced by behaviour) from ‘***teaching assistant***’ and ‘***best friend*** ‘***S***’. Data indicated a minor deterioration in state of health evidenced by a minor increase in some ES-CS, ‘**being bullied**’, ‘**being severely short-sighted**’, ‘**loneliness**’, and increasing ‘**social anxiety**’.

<u>Secondary</u> CTT, evidences a regressive narrative. This CTT had the greatest overall HFA narrative regression, compared with other CTT. This CTT had the greatest occurrence of CFA major negative tones compared with other CTT. Evidence of good support practice took the form of: Stable CSS continued to be provided by ‘***Mum***’, ‘***Dad***’ and ‘***his books***’, unstable positive CSS from ‘***supportive teachers***’, best friend ‘***S***’ and ‘***W***’. ‘***Reasonable adjustments***’ CSS were put in place. Data indicated a major deterioration in state of health evidenced by a major increase in ES-CS, ‘**feeling downtrodden**’, increasing ‘**social difficulties**’, and possible ‘**feelings of shame that he was not able to stand up for himself**’.

Sixth form CTT, evidences a progressive narrative. Evidence of good support practice took the form of: Stable CSS continued to be provided by '***Mum***', '***Dad***' and '***his books***', unstable positive CSS from '***supportive teachers***' and '***head of sixth form***'. '***Reasonable adjustments***' CSS continued. Data indicated a major improvement in state of health evidenced by no mention of new ongoing ES-CS, implying that he overcame previous CS or that these were considerably reduced, as well as likely to be due to having his autism diagnosis (aged 14 years) and accessing '***autism specific***' CSS.

University (BSc) CTT, evidences a regressive narrative. However, this CTT had the greatest occurrence of CFA major positive tones compared with other CTT. Evidence of good support practice took the form of: Stable CSS continued to be provided by '***Mum***', '***Dad***' and '***his books***', unstable positive CSS from '***Durrell wildlife trust***', '***disability team***', '***lecturers***', '***academic department***', '***good friend*** '***D***'', and '***fellow students***'. '***Reasonable adjustments***' CSS continued. Data indicated a minor deterioration in state of health evidenced by an incident in his final year resulting in ES-CS, and in addition to this OCD related symptoms and phobias.

University (MSc) CTT, evidences a stable narrative. Evidence of good support practice took the form of: Stable CSS continued to be provided by '***Mum***', '***Dad***' and '***his books***', unstable positive CSS from the '***disability/ASC service***', '***lecturers***', '***academic department***', '***societies***', '***Eureka***', and '***fellow students***'. '***Reasonable adjustments***' CSS continued. Data indicated a stable state of health evidenced by no change in or new ES-CS.

4.8 Andy’s story

4.8.1 Background and setting

The initial participant interview with Andy took place in his family home, where he was living with his ‘mum’ and ‘dad’. At the time of the interview Andy has just successfully completed a BSc in Law and was attending a new university doing a MSc.

4.8.2 Procedural steps 1-2: Overview

The holistic-content analysis (HCA) of Andy’s data is reflected in table 4.5 (a), the core transitioning themes (CTT) that emerged from his educational journey narrative. Two overarching TSTs were identified, namely ‘**academic**’ (Ac) and ‘**emotional-social**’ (ES). The ‘**emotional-social**’ (ES) subtheme has been grouped to include CS related to this heading such as; bullying, discrimination, friendship, group interactions, mental health (e.g., anxiety, fears, phobias, self-harm, stress), social anxiety, stigma, and so on.

Table 4.5 (a): Holistic-content analysis overview: Andy’s core transitioning themes (CTT) and transitioning sub-themes (TST). His age during each CTT is indicated within the brackets.

Core transitioning themes (CTT)					
	2nd Primary school (9-11 years)	**1st Secondary School (11-13 years)**	**2nd Secondary (13-17 years)**	**Sixth form (17-19 years)**	**University (BSc) (19-22 years)**
Transitioning sub-themes (TST)	Academic (Ac) Emotional-Social (ES)				

The categorical-content analysis (CCA) of Andy’s data, enabled a more in-depth examination of each CTT to look for patterns. For each CTT, Andy’s narrative was examined for the appearance of the specific concurrent stressors (CS) experienced by him (table 4.5 (b)) with the sections that follow giving context and describing them in detail. In the primary, secondary, sixth form and initially in the university CTTs their appearance appeared to be exacerbated by the overarching or major ES-CS ‘**being undiagnosed ASC**’ which was likely to have had impacts on both the ‘**academic** ‘ (Ac) CS and ‘**emotional-social**’ (ES) CS.

It is important to note that during the parental figure interview Mum shared detailed information about previous nursery and primary schools that Andy had attended prior to his 2nd primary school, contained within the interview transcription data where researcher notes have been made. However, the premise of this narrative is Andy's lived experience and because this was not shared by him it has not been included in this narrative data.

Table 4.5 (b): Categorical-content analysis overview: Andy’s transitioning sub-themes (TST) and concurrent stressors (CS). Table also shows the core transitioning themes (CTT) or timepoints where the CS occurred. 2nd P = second primary,1st S = first secondary, 2nd S = second secondary, 6 = sixth form, U = undergraduate university

Transitioning sub-themes (TST)	**Concurrent stressors (CS)**	**Time point(s)**				
		2nd P	**1st S**	**2nd S**	**6**	**U**
	Major CS: ‘being undiagnosed ASC’ (until aged 19 years) **(Un)**	**2nd P**	**1st S**	**2nd S**	**6**	**U**
	Major CS: ‘fear about standing out from his peers’ (ES)	**2nd P**	**1st S**	**2nd S**	**6**	**U**
	Major CS: ‘when people shouted’ (SnC)		**1st S**			
‘academic’ (Ac)						
	‘amount of detail needed to write in exams’					**U**
	‘doing assignments’				**6**	
	‘fear of academic level and amount of work’					**U**
	‘getting work in on time’				**6**	
	‘having to study research articles’					**U**
	‘not being allowed to do ‘normal’ math classes’			**2nd S**		
	‘poor handwriting skills’	**2nd P**				
	‘slow handwriting’	**2nd P**				
	‘struggling to move on to the next question in exams’				**6**	
	‘struggled understanding work set’				**6**	
	‘studying independently’					**U**
‘emotional-social’ (ES)						
	‘100% sadness’		**1st S**			
	‘50% sadness’			**2nd S**		
	‘25% sadness’				**6**	
	‘50% sadness for first year of university’					**U**
	‘40% sadness for 2nd and 3rd year of university					**U**
	‘anxiety telling mum he did not want to go to social groups’	**2nd P**				
	‘autism being used as a term used to insult others online’					**U**
	‘being away from home for the first time’					**U**
	‘being bullied’		**1st S**			
	‘being diagnosed with Autism’					**U**
	‘being ignored’			**2nd S**	**6**	
	‘being left out by peers’			**2nd S**		
	‘being timid’		**1st S**			
	‘concern about lecturers treating differently to peers because of ASC diagnosis’					**U**
	‘depressive symptoms’			**2nd S**	**6**	**U**
	‘difficulties developing new bonds and relationships with academic peers’					**U**
	‘difficulties going to social events’					**U**
	‘difficulties keeping a conversation going’					**U**
	‘difficulties participating in groups’					**U**
	‘difficulties when peers drink and party’					**U**
	‘discomfort in social groups’	**2nd P**				
	‘emotional-social difficulties impacted desire to do academic work’					**U**
	‘fear about ability to have a reasonable conversation’					**U**
	‘fear about having a mental health condition’					**U**
	‘fear of being alone’				**6**	**U**
	‘fear of being talked down to or treated as if not intelligent’					**U**
	‘fear that others would not consider him normal’					**U**
	‘fear that people would interact with him differently because of his autism diagnosis’					**U**
	‘feeling depressed because of the student accommodation’					**U**
	‘losing friendships’		**1st S**			
	‘low mood’		**1st S**			
	‘mood swings’					**U**
	‘not being able to talk to people’					**U**
	‘not knowing where to go during break times to avoid bullies and for a quiet space’		**1st S**			
	‘not wanting to join social groups’				**6**	
	‘not wanting to raise any concerns about himself from others’	**2nd P**				
	‘peers who didn’t want to learn’		**1st S**			
	‘running out of money by end of term due to overspending’					**U**
	‘sad days’			**2nd S**		
	‘shyness’	**2nd P**				
	‘social difficulties with peers’			**2nd S**		
	‘spending majority of time alone’					**U**
	‘unable to make new friends’		**1st S**			

‘emotional-social transitioning’ (EST)					
‘changing schools was nerve wrecking’			2nd S		
‘fear about the academic jump’		1st S			
‘fear of being alone’					U
‘fear of being bullied in new school’		1st S			

4.8.3 Procedural steps 1-2: 2nd primary CTT

4.8.3.1 Academic concurrent stressors (Ac-CS)

Andy wasn't aware of struggling academically during this CTT.

> "*I don't think I struggled … the work is quite simplistic so it's not too much of a struggle*".(P205/00:12:28)

His favourite subjects were, "*…math … I found it really rewarding to solve a certain equation…I enjoyed history, learning about different cultures and different time periods…*"(P205/00:12:47) However, he expressed physical difficulties which impacted his academic performance and resulted in Ac-CS such as '**slow handwriting**' and '**poor handwriting skills**'.

> "*I was a bit slow in my handwriting and I might have struggled with certain handwriting skills*".(P205/00:20:09)

Ac-CSS (Evidence of good support practice)
Andy recalled "*… I was part of a group … students who struggled with learning basic things*",(P205/00:14:58) and receiving Ac-CSS through this '***smaller learning group***'.

4.8.3.2 Emotional-social concurrent stressors (ES-CS)

Hesitantly and in a sad tone Andy shared that he may have attended some activities outside of school but that when he did this he experienced ES-CS due to, '**discomfort in social groups**', and that because of this '**anxiety telling mum he did not want to go to social groups**' CS resulted.

> "*…scouts. I think I might have but I wasn't really invested in them and I don't think I stayed long because I was just not very comfortable in social groups … I just couldn't interact well with the people in them, and I started to feel really uncomfortable with the fact that I was just in a place full of strangers I didn't know very well and just I think anxious, telling my mum I didn't want to go to these things anymore*".(P205/00:17:16)

He also had ES-CS because of ‘**fear about standing out from his peers**’ and when he did stand out from others, he stated that he felt, “…*a little bit anxious and* embarrassed”.(P205/00:18:51) Leaning away from the researcher Andy, looking sad, worried, and nervous, stated “*… I guess shy I would say. I kept to myself. I didn*’*t really talk that much. I tried to just keep to myself and not try to do or start any concern or stand out at all*”.(P205/00:18:16) This resulted in ‘**shyness**’ CS, and ‘**not wanting to raise any concerns about himself from others**’ CS.

ES-CSS (Evidence of good support practice)

Andy received ES-CSS from ‘***mum***’ and also possibly benefited from being part of a ‘***smaller learning group***’.

4.8.4 Procedural steps 1-2: 1st secondary CTT

4.8.4.1 Emotional-social transitioning concurrent stressors (EST-CS)

Andy mentioned being apprehensive about starting at this new school, "*... because I didn't get along with certain people so…. just bullying I guess…. The education, I guess ... Just the jump I guess*".(P205/00:23:03) This resulted in '**fear of being bullied in new school**' CS, and '**fear about the academic jump**' CS.

No EST-CSS

Andy said that his primary school provided no EST-CSS in terms of his transition into this CTT, that he was okay as long as he was with his friends, and that his parents encouraged him to manage this transition independently. "*...I was okay with it as long as I was with my friends…I think they* (parents) *just let me take on the ropes by myself I would say*".(P205/00:23:17)

4.8.4.2 The major concurrent stressor 'sensory challenges' (SnC-CS)

Andy mentioned that he experienced major CS because of '**sensory challenges**' (SnC), finding it particularly stressful when teachers and/or individuals raised their voices, leading on to him experiencing '**when people shouted**' CS.

> "*...there's a lot of shouting with the teachers which I hated. I can never stand when a person raises their voice. It made my heart ...like…jump and it made me want to cover my ears and stuff like that… It happened in most, yeah, so I didn't really feel comfortable in class there*".(P205/00:24:39)

4.8.4.3 Academic concurrent stressors (Ac-CS)

Ac-CSS (Evidence of good support practice)

Andy shared, "*I think we had also a small group but…you know... that's it*",(P205/00:24:50) receiving Ac-CSS from this '***smaller learning group***' but no other specific Ac-CSS.

4.8.4.4 Emotional-social concurrent stressors (ES-CS)

Andy stated that he got on academically, "*…fine, I guess. I just did the work. It was okay, yeah …*", but that the learning environment "*…was hell because students there didn't really want to learn at all. They just wanted to mess around and that made the teachers very kind of frustrated*".(P205/00:24:39) Expressing that ES-CS resulted because of '**peers who didn't want to learn**'.

Socially, Andy sadly recalled,

> "*No* (special friendships?)*… I think I just interact- I don't think I would call them special friends. I just think I had friends and I got along with them well enough … but then drifted apart from them*".(P205/00:12:01)

During play times, Andy shared that he liked doing role play with his peers, pretending to be,

> "*…certain people during play time, yeah. It was not that bad I would say. It wasn't full on…. Just* (sighs) *what did we-…? So, we just we act, just imagine … go into certain roles and pretending to be certain people, stuff like that*".(P205/00:15:34)

He spent "*… a little bit of time with them outside of school … I think I was mostly still by myself majority of the time … Just watching TV, I would say and just on my game console, something like that*".(P205/00:16:47)

Emotionally Andy described himself as, "*…timid I would say*",(P205/00:19:08) which resulted in ES-CS due to '**being timid**'. During this 1st secondary school CTT, Andy described experiencing '**low mood**' CS, and stated that he felt '**100% sadness**' CS, "*…really sad I would say*".(P205/00:28:28) Andy was sad and withdrawn describing his school as "*hell on earth*",(P205/00:21:09) full of "*horrible people*" (P205/00:21:09) who were "*bully-some*", (P205/00:21:09) how this led on to '**being bullied**' CS. During this time, he shared '**not knowing where to go during break times to avoid bullies and for a quiet space**' CS, how he searched for quiet places where there weren't "*horrible people*".(P205/00:21:09)

> "*… I think you had to be concerned with the environment because there are a lot of bullies at that school, so you had to be concerned of where you spend your*

> *free time at that high school… Probably just the quietest place I knew that was away from the kids who were just kind of horrible people … a quiet area for students who didn't want to spend time in a crowded area*".(P205/00:25:56)

When Andy began this 1st secondary school CTT, he recalled starting with the ES-CSS of two '***friends from previous school***', who later "*turned their backs*" on him resulting in '**losing friendships**' CS, which was one of his reasons that he wanting to leave this school, and another reason was being '**unable to make new friends**' CS.

> "*… they turned their back on me and that's why … why I wanted to leave … It's because* 'he' (friend one) *is kind of an arrogant person. He was just kind of in it for himself. He was always like this person who said to himself, "I'm the leader and we should do everything I say to do*"*. He is kind of full of himself so yeah …* 'He' (friend two) *was just quiet. He just went along to be honest. He didn't really say much*". (P205/00:26:37)

After two years Andy stressed that he couldn't continue in this school and that, with the help of his mum, he had to find a more suitable secondary school.

> "*I think about two years then I had enough. I didn't want to be there anymore, and we had to try to find a new school for me and tried to get out of it*".(P205/00:21:34)

ES-CSS (Evidence of good support practice)

Andy's '***mum***' and '***sister***' were both aware of his low mood and provided him with ES-CSS.

> "*Yeah, I think mum was the one who was mainly aware just because she's the one who mainly concerned with my emotional health … My … my sister I think is somebody who, someone of emotional support*".(P205/00:28:36)

Initially he had ES-CSS from two '***friends from previous school***'. Andy remembered that he was offered ES-CSS during his 1st secondary school, through a '***smaller learning group***', and that there were times when '***student support services***' would ask to see him, "*…I think the people who were there for supporting the students … I think I saw them on specific times where they asked to see me and that was it*". (P205/00:27:37) However, he chose not to fully engage with this support independently.

4.8.5 Procedural steps 1-2: 2nd secondary CTT

4.8.5.1 Emotional-social transitioning concurrent stressors (EST-CS)

When Andy moved to this new secondary school, he mentioned that this resulted in ES-CS because '**changing schools was nerve wrecking**', he reasoned that this was due to him not knowing anyone at this school. He stated that he was fearful that he may have the same experiences with his new peers as he had done in his previous school, although he was happy recalling that he did in fact get along with his new peers "*very well*" in time.

> "*Nerve-wrecking because I didn't know anyone, and I didn't know if these students were going to be any better than the ones at* 'L' (1st secondary school)*… but in time I got along with those people and I got along with the class very well. I interacted with a lot of people pretty well definitely*".(P205/00:30:08)

4.8.5.2 Academic concurrent stressors (Ac-CS)

Academically Andy felt that he did well in his 2nd secondary school, although he expressed unhappiness at being put in foundation classes, resulting in Ac-CS because he was '**not being allowed to do** '**normal**' **math classes**' and '**fear about standing out from his peers**'.

> "*Very well I would say. I was put in the foundation year for both math and English, for those… A lower level so like C grade math… Not great. I didn't really- because only a small amount of students were put into foundation while the others were put into- most of them were in higher so I just felt like it was like- it felt standout-ish. I wanted to just do the normal math I guess I would say*".(P205/00:31:43)

<u>Ac-CSS</u> (Evidence of good support practice)

Andy stated that Ac-CSS was not provided to him, other than through '***smaller classes***', around 12 students, and that he had to, "*…mainly work it out by myself to be honest*".(P205/00:32:50)

4.8.5.3 Emotional-social concurrent stressors (ES-CS)

In this CTT, when he experienced CS due to '**being ignored**' and/or '**being left out by peers**', he shared that he would, "…*go home… yeah, I think so* (feeling less sad at home). *I just spend some time just trying to resolve it and yeah, I just go back to normal*".(P205/00:36:10) Continuing, he explained that he didn't tend to share his emotions and feelings with others, "… *I think I kept it* (my emotions) *to myself*".(P205/00:36:36)

Emotionally, Andy expressed '**50% sadness**' CS during this CTT, "*I think half* (the circle)".(P205/00:45:50) Andy, with positive verbal and non-verbals, stated that he was able to make '***good friends***' at his 2nd secondary school, and that these friends appeared to provide him with ES-CSS. He stated that he became more talkative during this CTT and that he spent time together with his peers in and out of school. He inferred that this was easier for him because the school had a small number of peers to interact with.

> "*It was a small area to interact with… I think I had good friendships there and I was more talkative there and all that… I think we hung out. We went to each other's houses. We went to sit in- I think we even hung out as a class during outside school hours*".(P205/00:33:47)

Even though, Andy expressed that he was a lot better in his 2nd secondary school he still appeared to have '**sad days**' CS and '**depressive symptoms**' CS, during this time. ES-CS triggers were '**social difficulties with peers**', in particular '**being left out by peers**' and '**being ignored**' (by peers).

> "*Better but still not that great. I had my episodes of depression. I was a bit sad in certain days, all that… Yeah, I think it depended on the day really… I think if I felt like I was being left out or just ignored, yeah, stuff like that… Yeah, social trigger*". (P205/00:35:15)

ES-CSS (Evidence of good support practice)
Friendship ES-CSS was provided by some '***good friends***'. Forming friendships appeared to be easier due to there being '***smaller classes***' with less peers to interact with in his school. There was a continuation of ES-CSS from '***Mum***' and his '***sister***.

4.8.6 Procedural steps 1-2: Sixth form CTT

4.8.6.1 Academic concurrent stressors (Ac-CS)

During this CTT Ac-CS were '**doing assignments**', '**getting work in on time**', and when he '**struggled understanding work set**'.

> "*I struggled a bit I would say in certain pieces of the work and sometimes I got in work a bit late, but I always did the work. I always gave the work in because yeah, I may have struggled to understand it at times, and I tried to get enough down something like that. I had to spend a lot of time on the textbook trying to analyse a certain bit of it*".(P205/00:41:25)

Although hesitantly he shared his excitement at being able to specialise on, "*... certain subjects rather than mixed because, you know… Yeah, specialising I would say… I chose to do modern history, law, and business studies*".(P205/00:39:15)

He expressed how using a computer in sixth form helped him with his, '**struggling to move on to the next question in exams**' CS.

> "*I think it* (a computer) *was just faster to be honest for me and I think they were concerned with understanding the work or if I was struggling with the same question, I wanted to go onto the other question I could do that quite easily without concerning myself with the amount of paper I had*".(P205/00:42:59)

<u>Ac-CSS</u> (Evidence of good support practice)

Andy said that his sixth form provided Ac-CSS through '***classes to choose A-level subjects***'.

> "*They offered students a chance to participate in certain classes, certain subject areas because this was the time where we just chose specific areas to study*".(P205/00:37:56)

Ac-CSS was provided by '***student support services***', who put '***reasonable adjustments***' in place for exams, without a formal autism diagnosis, in the form of '***extra time***', '***a computer***', and '***bathroom breaks***' (in exams).

> "*Yeah, I think I was recommended to certain people to help with my work to help me understand it a bit more, just… I think they were just student support I would say, yeah… I think when I went onto college it was access to a computer. I think I was…. yeah and I think I was entitled to bathroom breaks as well*".(P205/00:41:25)

4.8.6.2 Emotional-social concurrent stressors (ES-CS)

Prior to starting sixth form Andy was apprehensive about the ES side of college, particularly "*…being on my own I would say*".(P205/00:39:49) He described his ES-CS triggers as "*…being by myself to be honest or just feeling ignored, stuff like that*",(P205/00:46:44) which resulted in CS, '**fear of being alone**' and '**being ignored**'. Andy recalled 'good' first memories of sixth form, stating that he enjoyed having more free time, independence and being able to work from home some days.

> "*Yeah. I think it was good. It was more free; I would say to just do your own thing to be honest and since the hours were fixed I would say they were quite good. Certain days I didn't have to go in. I could just stay at home and do my work there. Certain days it was just in the morning and I could go home, stuff like that so yeah*".(P205/00:38:28)

Describing how this sixth form CTT was better than his 2nd secondary school but that he still felt sad at times due to '**fear of being alone**' CS, and he stated that he had '**25% sadness**' CS during this CTT.

> "*I was better than in high school. I think I was still emotional at times and I still felt by myself and that made me a bit sad, but I don't think they were as bad as they were in high school… "I would probably say quarter* (25% sad)".(P205/00:45:14)

He shared that he received ES-CSS from '***two peers***' but went on to say that he still spent a lot of time on his own during his breaks either in the student support area, local village, or park.

> "*I think I had two people I interacted with the most… I think a lot of the time I was by myself, I was just walking around because they had different classes at*

> *different times and all that and it was just like- so I think I was mostly by myself and I mostly just went to the student support area, because we were able to move around, not just around the college but also the surrounding areas so I think I might have just gone down to the local village around that area or I went to the park, get food there or just sit somewhere*”.(P205/00:43:51)

He recalled being encouraged by Mum to join social groups, but this resulted in him experiencing ‘**not wanting to join social groups**’ CS.

> “*I’m not sure to be honest. I think I was encouraged by my mother to participate in certain social groups, but I didn’t really want to. I just wanted to be doing my own thing and not be pressured into a group*”. (P205/00:40:07)

ES-CSS (Evidence of good support practice)

‘***Two peers***’ provided Andy with some CSS during this CTT. ES-CSS continued to be provided by ‘***Mum***’, his ‘***sister***’, and ‘***student support services***’.

4.8.7 Procedural steps 1-2: University CTT

4.8.7.1 Emotional-social transitioning concurrent stressors (EST-CS)

I (the researcher) asked Andy "*…prior to you coming to* 'the chosen uni.' *were you aware of any support that might be available to you*?" to which he responded that he wasn't aware of any until he was at university. Prior to starting university Andy expressed continuation of ES-CS, '**fear of being alone**', fearing "*...the social areas, if it was just going to be me and that was it*".(P205/00:51:44)

<u>EST-CSS</u> (Evidence of good support practice)

Prior to starting university Andy's sixth form provided him with EST-CSS in the form of; '***classes about going to university***', '***life skill lessons***', '***social skill lessons***', '***educational skill lessons***', '***help choosing a university***', '***help writing a personal statement***', '***help choosing a degree***', and '***help going to university open days***'.

> "*... during the final year of college, we had a main class that was concerned with integrating into university and then I think the majority of that was just living skills and social skills and educational skills, stuff like that and I also think majority of the time was preparing the choices, which universities we were going to pick and writing that- what's that-... Yeah, a personal statement, what you wanted to do, what were your interests, how were they linked to this degree you're interested in doing at that university, stuff like that... Yeah. I think if you had the spare time and you didn't have any classes that day if there was an open day available, yeah, we'd go to that*".(P205/00:47:17)

4.8.7.2 Academic concurrent stressors (Ac-CS)

Prior to starting university Andy was most excited about what he was about to learn academically.

> "*I think just the learning mostly, just the new experience... Academically. I would probably say I was excited to advance myself educationally*".(P205/00:51:00)

Although he was fearful about, "*... probably the level of work that was going to be required and I had to dedicate myself to this work fully and stuff like that*"(P205/00:51:24) and experienced '**fear of academic level and amount of work**' CS.

Academically Andy's greatest Ac-CS shared was '**seminars**', particularly, "... *seminar participation*".(P205/00:57:14) He also described experiencing CS due to; '**amount of detail needed to write in exams**' and '**studying independently**'.

> "*Academically so far I would probably say probably the exams in university I would say… Just the amount of detail you probably have to write and the amount of time you have to dedicate yourself to self-study and just make yourself reinforce the knowledge that you've taken in and stuff like that*". (P205/01:13:55)

Andy also described '**having to study research articles**' CS, how this was challenging for him.

> "*I'd probably say the outside research that was required for certain work… Just because you had to look at long pieces of work, these sources, these articles which were a drag, and they could… Yeah. Well, they could be hard to understand, and you would spend a lot of time just looking through it just to find a certain small part that you needed for your work and all that and yeah*". (P205/01:07:37)

Ac-CSS (Evidence of good support practice)
Following Andy's autism diagnosis, the university put in '***reasonable adjustments***' for exams, '***a computer***', '***smaller room***', '***rest breaks***', and '***25% extra time in exams***'.*(P205/00:55:27)*

Andy received additional specialised Ac-CSS (ES-CSS) through '***Disabled Student Allowance (DSA)***' which provided him '***a laptop***', '***an audio recording device***', and '***study skills tutor***.(P205/00:55:45) Andy found using '***an audio device***' in lectures and playing back the information, "*…was helpful. I managed to put it on, listen back to the recording stuff like that*".(P205/01:07:08)

Andy met with his '***specialist study skills tutor***' (for help with planning and learning academic terms), and his '***specialist autism mentor***' (for ES-CSS), weekly.

> "*Well, I needed access to the study skills… Once a week… I think it was mainly the planning of my work, I think how to answer questions, how to understand them, looking at specific terms of words that were used and understanding what that word was saying I needed to do stuff like that*".(P205/01:03:56)

Andy also stated that he received Ac-CSS from his '***academic department***', that he met with his '***personal tutor***' once a term to talk about any Ac-CS issues he was experiencing.

> "*Well ... my personal tutor ... I was required to meet up with once a term, but I could also email that person just to talk to about issues I was having with the course, stuff like that… Yeah. Yeah, it was a good service, yeah*".(P205/01:04:49)

He also received '***academic department***' support with seminar participation, that they '***coached him on how to interact with his peers during seminars***' and '***how to get his point of view across***'.

4.8.7.3 Emotional-social concurrent stressors (ES-CS)

Andy found the first week of university,

> "*…a bit nerve-wrecking ... being away from home for the first time and just being in this depressing little room because I was at the least expensive part of the student accommodation in ... university. I was just like, 'Ugh'…*".(P205/00:49:52)

This resulted in '**being away from home for the first time**' CS and '**feeling depressed because of the student accommodation**' CS. Emotionally, Andy described this period as his 'least happy' time at university, that '**emotional-social difficulties impacted desire to do academic work**' CS.

> "*Yeah, and I think that* (the first term of university) *was the least happy part of the university time was being at that accommodation and just like…*".(P205/00:50:31)

> “*Yeah, I think … emotional … it affected my ability to want to do work I would say*”.(P205/01:10:42)

University was the first time Andy lived independently, something he prepared for by learning basic cooking, living skills such as looking after a house, himself, washing, and money management. The only area he mentioned struggling with at university was ‘**running out of money by end of term due to overspending**’ CS.

> “*I think just basic cooking skills or just like living skills I would say, just looking after the house, look after myself while I was by myself basically… Yeah, I think washing is okay. It took a while but yeah. Money management is okay. I only really struggled with handling my finances when it was nearing the end of a term, because I might’ve overspent money and all… But I didn’t waste money on alcohol or stuff like that, so it wasn’t too bad*”.(P205/01:00:36)

Andy wasn’t happy with his first student accommodation, moving several times before he settled, especially because of ‘**difficulties when peers drink and party**’ CS in the accommodation.

> “*I just really wasn’t happy with the environment to be honest. It was … environment of partying and just not a great environment to be in*”.(P205/01:02:07)

Eventually he was put in accommodation that felt a lot better to him, because it was ‘less depressing’, had its own bathroom, and had a more comfortable bed.

> “*The accommodation was so much better. Having access to my own bathroom and just the openness of the room itself, it was better to work in, it was better to sleep there. The bed was more comfortable and just the room was brighter and less depressing and all that, so yeah, it was better*”.(P205/01:02:54)

Andy described how ‘***Mum***’ was concerned about his ‘**social difficulties with peers**’ CS (and Ac-CS) and contacted the ‘***wellbeing***’, ‘***autism service***’ for ES-CSS (Ac-CSS), however, she was informed that he was not able to fully access this CSS without an autism medical diagnosis, which he then got.

> “*… year one of university, term one… Yeah, got my place at … university, but I couldn’t access the health services or specific services I needed to …help with*

> *work or socialising within the university and apparently I needed a certain medical diagnosis for it, so I was telling my mum that and she said, 'Well let's talk to this doctor I know who can help us to see if you can be diagnosed with autism'. So, we went to see this doctor … and after it was done he said, 'Yeah, I would believe you're on the spectrum', and he wrote this letter of diagnosis just confirming*".(P205/00:00:41)

Being diagnosed with autism meant that Andy could now access '***autism specific***' CSS, meeting with an '***autism practitioner***' once a week.

> "*I think halfway through the second month I would say… I would say* (autism practitioner) *was the first one… I think it was social, just like a meeting once a week to talk about how I was doing in the university, stuff like that*". (P205/00:53:59)

When Andy was diagnosed with autism during his first year at university this resulted in '**being diagnosed with autism**' CS, he stated that he worried about having an autistic label, because of '**autism being used as a term used to insult others online**'.

> "*…I just knew it was kind of an insult online, so that kind of made me concerned… An insult, like so people on certain social media will use it to insult others intelligence, stuff like that*".(P205/00:04:58)

He also went on to express many other ES-CS whilst at university such as '**fear about ability to have a reasonable conversation**', '**fear about having a mental health condition**', '**fear about standing out from his peers**', '**fear of being talked down to or treated as if not intelligent**', '**fear that other's will not consider him normal**', and '**fear that people would interact with him differently because of his autism diagnosis**'.

> "*I was concerned… because I didn't really want to have something that made me different from other people that made me stand out which made people look at me, people interact with me differently than they did before*".(P205/00:04:06)

> "*Just a little concerned. I didn't really want to have a mental condition to be honest. I just wanted to be a normal- what I would consider to be a normal person and just not have anything that made me stand out or made me look like*

> *someone who could not have a reasonable conversation with or like have a conversation which required- which were kind of high… high … knowledge. I certainly didn't want to be talked down to or treated as if I was not intelligent enough to have a conversation with or something like that*".(P205/00:07:50)

Andy shared how he found some aspects of his diagnosis reassuring such as discovering it didn't mean he had low intelligence or had a low IQ, and that his autism was likely to be the reason for his '**social difficulties with peers**' CS, '**depressive symptoms**' CS, '**mood swings**' CS and Ac-CS.

> "*I think I just listened to what the doctor who made my diagnosis said about it and I think I was more reassured then, because I knew it wasn't something that stated that I had a low intelligence or a low IQ. I think it just meant that it was different for certain people so it could mean something more social problems or more learning problems, stuff like that… that it could be linked to my depression so yeah, so he did state that I was more prone to being depressed than people without autism so it kind of explained my certain mood swings throughout the years and how I broke down at certain points earlier*".(P205/00:05:29)

Andy didn't seem at all worried about disclosing his autism diagnosis to university staff because he presumed that they understood what autism meant and he knew that this would be confidential.

> "*… I think it was okay because I was giving this information to people who probably understood what autism was and I knew it was confidential, so I didn't have to worry that much*".(P205/01:08:37)

Although, he expressed some concern about his lecturers knowing, "*… because I didn't know if they knew it well enough… they would treat me different from the rest of the students*".(P205/01:09:01) This appeared to trigger '**concern about lecturers treating differently to peers because of ASD diagnosis**' CS.

During this CTT, Andy experienced social barriers resulting in '**difficulties going to social events**' CS, however, he did share that he went to the daytime freshers' events but avoided night parties due to ongoing '**difficulties when peers drink and party**' CS.

> "*I guess going to the social events really… Yeah, I think I only went to the daytime fresher events. When it was at night I was like, 'Nope', because I think there was more drinking and partying and all that and I just did not enjoy that at all*".(P205/00:52:12)

He mentioned that he experienced '**50% sadness for first year of university**' CS, reasoning that he felt like this because of his '**social difficulties**', prior to forming friendships through the Christian Union Society.

> "*… I would say it was half-half* (50% sadness)*… I think it was just a struggle socially, because I wasn't spending a lot of time with these people* (Christian Union) *at that time I would say*".(P205/00:59:42)

When asked to describe how sad he felt during his second and third university years, compared with 50% in the first year, he stated that he had '**40% sadness for 2nd and 3rd year of university**' **CS**.

> "*I think* (second and third year of university) *40% would be sad …*".(P205/01:13:12)

Socially Andy shared his biggest challenge during this university CTT was '**difficulties developing new bonds and relationships with academic peers**' CS, that he had only talked to one academic peer the whole of his degree. However, Andy went on to describe how he did develop strong bonds with some peers through the Christian Union Society, how some of these peers he is still in contact with now.

> "*… I think just developing new bonds and relationships, so I didn't manage to do that in my lectures, so I did not really talk. I think I talked to one person but then that was about it. I didn't really feel like we had that strong of a bond though so I mainly relied on my Christian- I mean my social development was mainly with the Christian Union I would say… Yeah, I think it was a society in the university… I'm still in contact with some of them so yeah*".(P205/00:58:02)

The greatest social challenges that Andy disclosed were '**difficulties keeping a conversation going**' CS and '**difficulties participating in groups**' CS.

> "*Socially I guess it would be being able to keep a conversation going for a long amount of time and just to be participating in groups I would say willingly*".(P205/01:14:47)

Continuing he explained that his greatest emotional challenges at university were '**spending majority of time alone**' CS and '**not being able to talk to people**' CS.

> "*I think spending a majority of my time alone …not being able to talk to people*".(P205/01:15:24)

Andy expressed that his greatest achievement during this CTT was, "*I guess just keeping a healthy lifestyle I would say*".(P205/01:17:08) He continued proudly that his greatest achievement overall at university was successfully completing his three years and getting his BSc, "*…probably just getting through the three years of university and getting that degree*".(P205/01:15:45) Andy described his greatest emotional achievement at university as; "*I think probably accepting that there's a problem with my life and just trying to fix it… depression, like accepting the autism, stuff like that*".(P205/01:16:31) Finally, he proudly shared his greatest social achievement at university, as "*…developing a vast amount of relations with other people in the CU* (Christian Union) *I would say*".(P205/01:16:06)

ES-CSS (Evidence of good support practice)

Following mum informing the university that Andy was struggling, ES-CSS was provided by the '***wellbeing/Autism service***'. Once Andy was diagnosed with autism, he then regularly received ES-CSS from an '***autism practitioner***'. Andy shared that his '***specialist autism mentor***', helped him 'expand' his social skills, fit in with his peers, as well as general day to day Ac-CS and ES-CS.

> "*…I think yeah, through* 'mentors name', *yeah, I did. I think she was paid for DSA… Yeah, I think it helped me well enough. I think it helped me expand my social skills and also my academic understanding, stuff like that. Its helped me to fit in more with the university lifestyle I would say*". (P205/00:56:17)

During Andy's third year of university, he was diagnosed with depression, and he continued to suffer with '**depressive symptoms**' CS when interviewed.

> "*… I was only recently diagnosed with depression I think during my third year at university. I just felt one day that I was just down in the dumps and that I just didn't know- I was just not- nothing was making me happy at that time. I was contacting my mum saying, 'Mum, I'm really not happy. I don't know what to do', and she just recommended I go to my GP, see if I could get a diagnosis and yeah, I think it was clear that I was really depressed and that was when I started going on medication and stuff like that. I was also recommended trying to access some services for it*".(P205/00:09:36)

After Andy's depression diagnosis, he accessed ES-CSS through the university's '***counselling service***', and by attending their '***anxiety-depression talks***'. He stated that both of these CSS helped him to 'open up' about his feelings as well as receiving ES-CSS from his '***GP***' and '***anti-depressant medication***'.

> "*Yes. I think at the end I accessed a counselling service. I had four sessions where I was able to open up about how I was feeling and stuff like that and also, I think they were running these talks about anxiety, depression, stuff like that… Yeah, they were good. They were definitely good*".(P205/01:12:13)

As mentioned earlier, Andy made friendships and received social CSS from the '***Christian Union Society***' in the university. Specifically for his social challenges the '***Wellbeing/autism service***' suggested he attend weekly support meetings in the form of '***Eureka***' the autism social group. In these meeting, he got ES-CSS in the form of '***peer support***' from others who, like him, were on the spectrum which he found helpful.

> "*Yeah. They recommended Eureka which was able to interact with other people on autism, stuff like that and also regular meet-ups each week and yeah, I think that was it*".(P205/01:09:53)

Throughout this CTT, Andy described receiving ongoing ES-CSS from his '***Mum***' whom he would "*…talk to my mum everyday but that was about it… Every two weeks I went home for the weekend*".(P205/01:10:19)

4.8.8 Procedural step 3

The categorical-form analysis (CFA) of Andy’s data enabled me (the researcher) to gain in-depth insight into Andy’s linguistic dialogue, namely his tones of voice and non-verbal communication. This was performed by using Andy’s fabula notes and tagging frequency of nonverbal (sjuzet) occurrences within his narrative statements, using reflective diary entries. CFA data was categorised into seven varied tones, and non-verbals, and frequencies calculated. CFA data relating to Andy’s state of health, positive and negative tones, and non-verbals (n=5), were then used to illustrate tonal frequencies within his narrative. Table 4.5 (c) details fabula notes and tagged positive and/or negative nonverbal calculation for each CTT, which will be discussed in more detail in next sections (appendix 4.5 (a) details a breakdown of these calculations).

Table 4.5 (c): The positive and negative linguistic tones and nonverbals used by Andy during his interviews that were identified using the sjuzet data applied to statements made within the context of themes and subthemes.

		Percentage category occurrence of positive and negative linguistic tones/nonverbals in each CTT				
Tone or non-verbal used (frequency)	**Category (frequency)**	**2nd Primary**	**1st Secondary**	**2nd Secondary**	**Sixth form**	**University**
very quiet tone (28) sad (looking down/closed communication, withdrawing into self) (23) nervous / closed communication / leaning back / head leaning back / leaning away from the interviewer (17) worried (14)	**Negative** (66*)	18%	> negative 41%	0%	9%	32%
positive open communication / leaning forward towards interviewer (79)	**Positive** (71**)	14%	0%	14%	23%	> positive 49%

*Negative (-16 tones (1 worried, 4 sad, 7 quiet and 1 nervous) did not relate specifically to a CTT and has been excluded) (Total n=4)
**Positive (-8 tones did not relate specifically to a CTT and have been excluded) (Total n=1)
NB: Not included in this table were factual and hesitant (Total n=2)
>Indicates the greatest frequency of tone type occurrence amongst all the CTTs

4.8.9 Procedural step 4

Holistic-form analysis (HFA) combined HCA, CCA, CFA results, using the HFA scoring matrix (chapter 3, section 3.6.6.3, table 3.3), to produce an HFA numerical score that could then be attributed to a CTT (calculation shown in appendix 4.5 (b)). This score was then compared with another CTT to gauge Andy's narrative progression or regression. HFA score also enabled consideration of the structure of Andy's narrative, how he positioned himself within it, his typology, cohesion within his narrative and any turning points. The 'overall' core of Andy's transitioning story showed a regressive, progressive, regressive, narrative (figure 4.5 (a)). The limitations of using a scoring matrix are discussed in section 6.7.

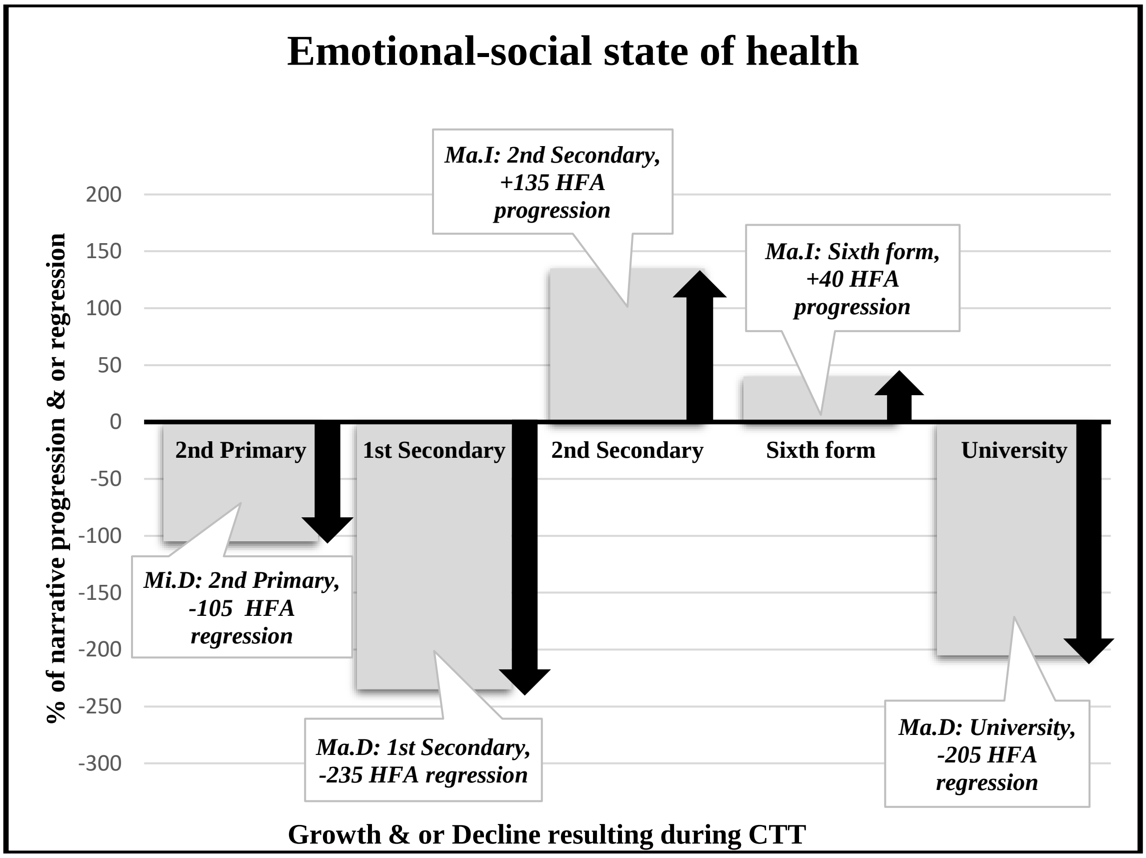


Figure 4.5 (a): Holistic-form: Narrative regression, progression, regression, of Andy's Core Story, CTT, TST, in relation to state of health. MiD = Minor deterioration in state of health / MaD = Major deterioration in state of health / MiI = Minor improvement in state of health / MaI = Major improvement in state of health

The 2nd primary CTT demonstrated -105 HFA regressive narrative decline (figure 4.5 (a) column 1). Andy's data indicated a minor deterioration in state of health (MiD) due to an increase in some ES-CS, particularly '**social anxiety**'.

The 1st secondary CTT demonstrated -235 HFA regressive narrative decline (figure 4.5 (a) column 2). This CTT had the greatest occurrence of CFA major negative tones discussing ES-CS experiences compared with other CTT (table 4.5 (d)). Thus, Andy's data indicated that he experienced a major deterioration in state of health (MaD) during this CTT due to a major increase in ES-CS, feeling '**100% sadness**', '**being bullied**', increasing fears, '**low mood**' and sound sensitivities '**when people shouted**'.

The 2nd secondary CTT demonstrated +135 HFA progressive narrative growth (figure 4.5 (a) column 3). Andy's data indicated a major improvement in state of health (MaI) due a major improvement in ES-CS, feeling '**50% sadness**' versus 100% sadness in the previous phase, as well as, no mention of anxieties or fears, although onset of '**depressive symptoms**', implying that he overcame previous CS or that these were considerably reduced.

The sixth form CTT demonstrated +40 HFA progressive narrative growth (figure 4.5 (a) column 4). Andy's data indicated a major improvement in state of health (MaI) due to continued major improvement in ES-CS, feeling '**25% sadness**' versus 50% in the previous phase, only one mention of fears, although he did continue to experience '**depressive symptoms**', implying that he overcame previous CS or that these were considerably reduced.

The university CTT demonstrated -205 HFA regressive narrative decline (figure 4.5 (a) column 5). This CTT had the greatest occurrence of CFA major positive tones discussing Ac-CS, ES-CS and CSS experiences, compared with other CTT. However, Andy's data indicated that he experienced a major deterioration in state of health (MaD) due to ongoing ES-CS, feeling '**50% sadness**' in 1st year and '**40% sadness**' the rest of university, versus **25%** in the previous phase, '**social anxiety**', '**mood swings**' and continuation of '**depressive symptoms**', which resulted in a diagnosis of depression.

4.8.9.1 Andy's Typology

HFA revealed Andy's typology throughout his narrative as a 'rational, shy, and gentle' typology. Typology will be discussed in detail in step 6, section 4.8.11.

Table 4.5 (d): Calculation of Andy’s Holistic-form analysis score combining HCA, CCA, CFA narrative data. HCA = holistic-content analysis, CCA = categorical-content analysis, CFA = categorical-form analysis, HFA = holistic-form analysis, CTT = core transitioning theme, CS = concurrent stressor, Ac = academic, ES = emotional-social, MiD = minor deterioration to state of health, MaD = major deterioration to state of health, MiI = minor improvement to state of health, MaI = major improvement to state of health

	Holistic-form analysis frequency and score									
	Primary		**1st Secondary**		**2nd Secondary**		**Sixth form**		**University**	
(i) Previously identified CS	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**
Major Ac-CS (impacting state of health) $^{(f \text{ x } -5)}$	f = 1	n = - 5	f = 1	n = - 5	f = 1	n = - 5	f = 1	n = - 5	f = 1	n = - 5
Minor ES-CS $^{(f \text{ x } -5)}$	f = 4	n = - 20	f = 8	n = - 40	f = 6	n = - 30	f = 5	n = - 25	f = 24	n = - 120
Major ES-CS $^{(f \text{ x } -10)}$	f = 3	n = - 30	f = 4	n = - 40	f = 3	n = - 30	f = 3	n = - 30	f = 3	n = - 30
(ii) CFA linguistic (nonverbal) results	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**	**Category (frequency)**	**Category (HFA total score)**
Minor negative CFA $^{(f \text{ x } -25)}$	-	-	-	-	-	-	-	-	-	-
Major negative CFA $^{(f \text{ x } -50)}$	-	-	f = 1	n = - 50	-	-	-	-	-	-
Minor positive CFA $^{(f \text{ x } +25)}$	-	-	-	-	-	-	-	-	-	-
Major positive CFA $^{(f \text{ x } +50)}$	-	-	-	-	-	-	-	-	f = 1	n = + 50
(iii) State of health	**Category (HFA total score)**		**Category (HFA total score)**		**Category (HFA total score)**		**Category (HFA total score)**		**Category (HFA total score)**	
MiD $^{(f \text{ x } -50)}$	n = - 50		-		-				-	
MaD $^{(f \text{ x } -100)}$	-		n = -100		-		-		n = -100	
MiI $^{(f \text{ x } +50)}$	-		-		-		-		-	
MaI $^{(f \text{ x } +100)}$	-		-		n = +200 (2)		n = +100		-	
	Total primary HFA score		**Total 1st secondary HFA score**		**Total 2nd secondary HFA score**		**Total sixth form HFA score**		**Total university HFA score**	
	n = - 105 (regressive narrative decline)		n = - 235 (regressive narrative decline)		n = + 135 (progressive narrative growth)		n = + 40 (regressive narrative decline)		n = - 205 (stable)	

4.8.10 Procedural step 5

To be able to illustrate to the reader Andy’s ability to adapt to a CTT, I encompassed Andy’s HCA, CCA, CFA, HFA data into the ‘educational transitioning model’, which visually detailed; (1) any CS that impacted his state of health, (2) ‘self’ characteristics, (3) concurrent stressor support (CSS), (4) previous CTT state of health compared with current state of health. The educational transitioning models (figures 4.5 (b)-(f)) summarise Andy’s lived experiences and educational journey in relation to his state of health.

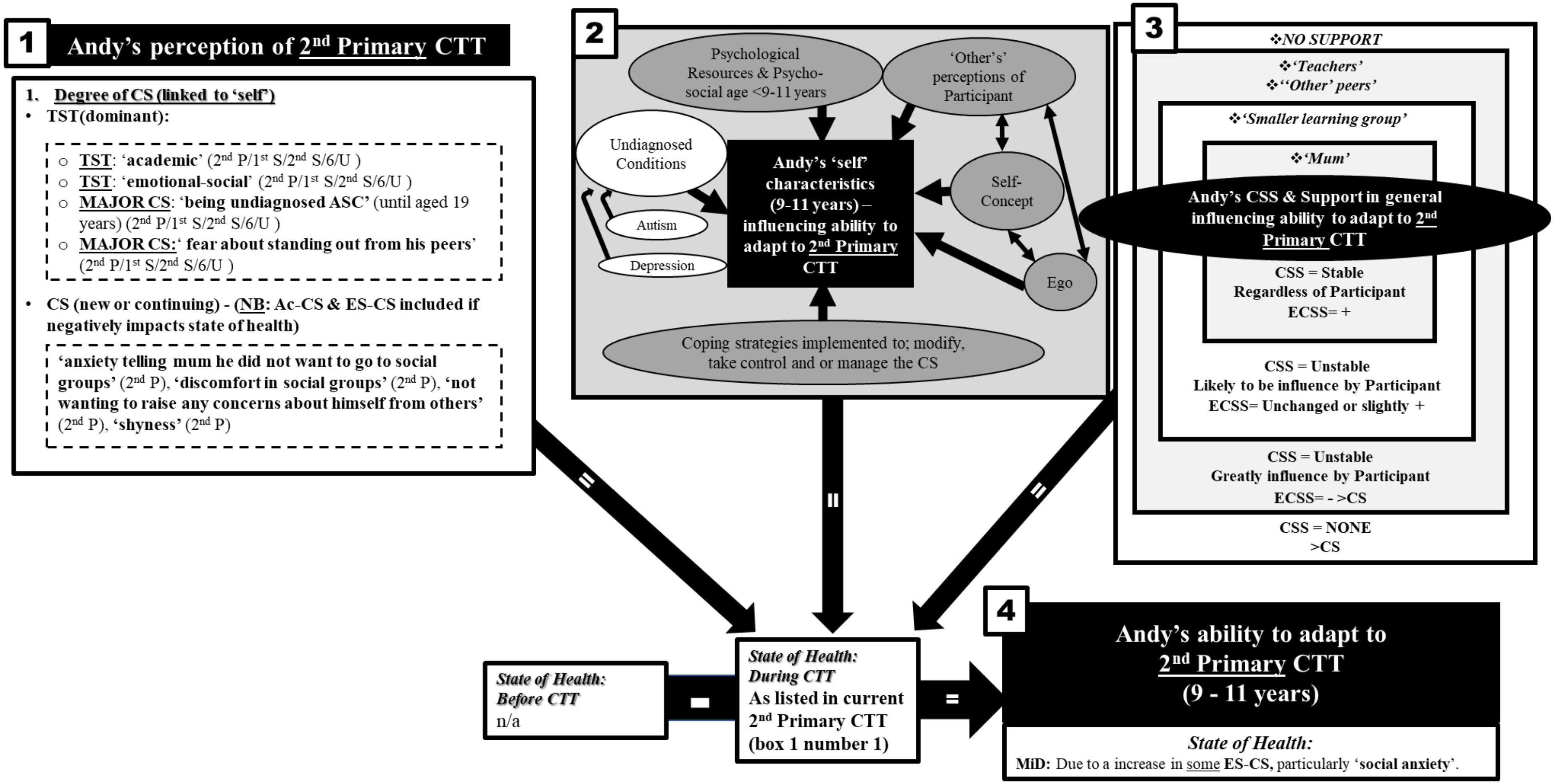


Figure 4.5 (b): Educational transitioning model representing Andy's ability to adapt to the 2nd primary CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268]
For abbreviations see chapter three, table 3.4.

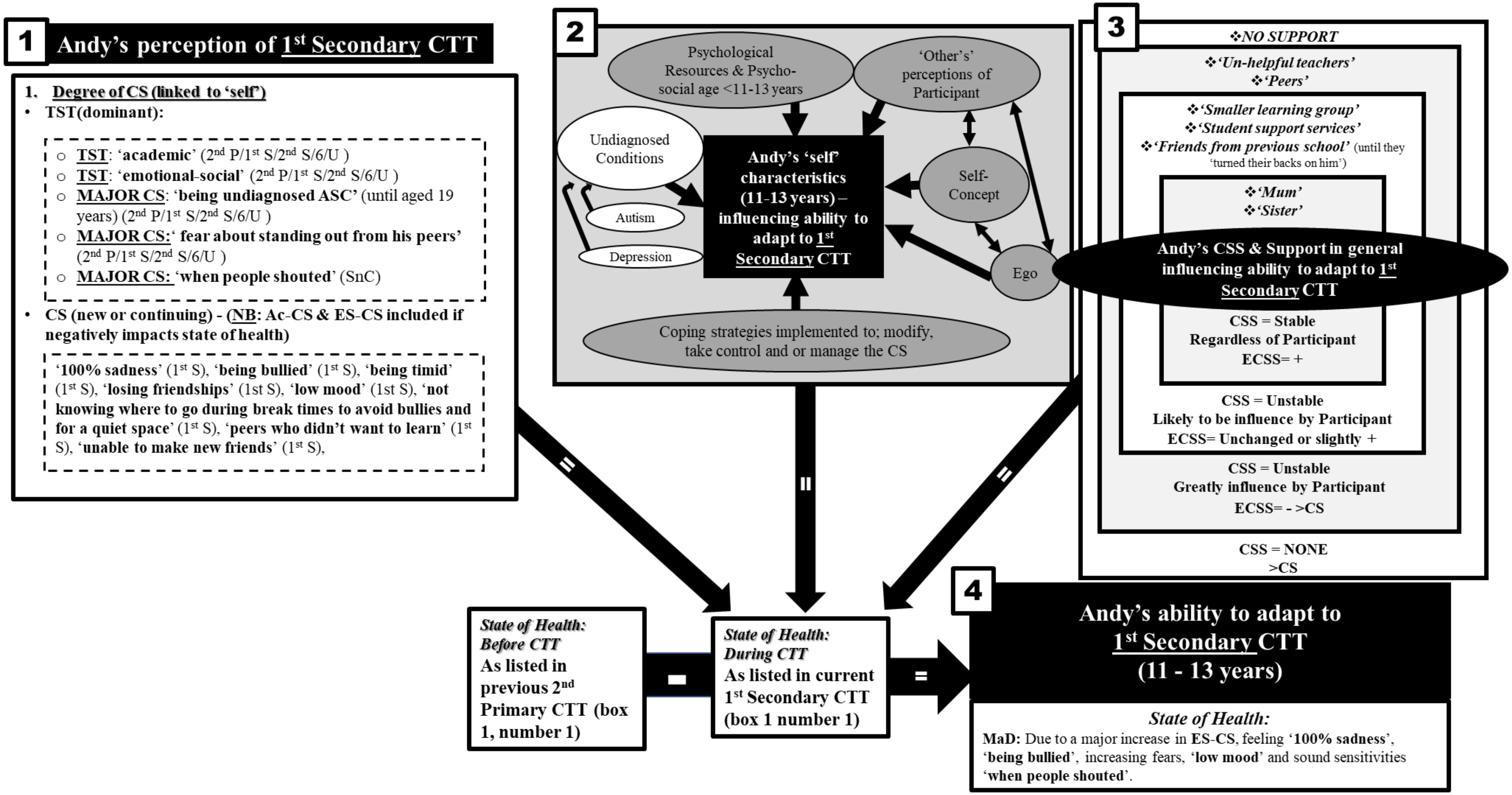


Figure 4.5 (c): Educational transitioning model representing Andy's ability to adapt to the 1st secondary CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

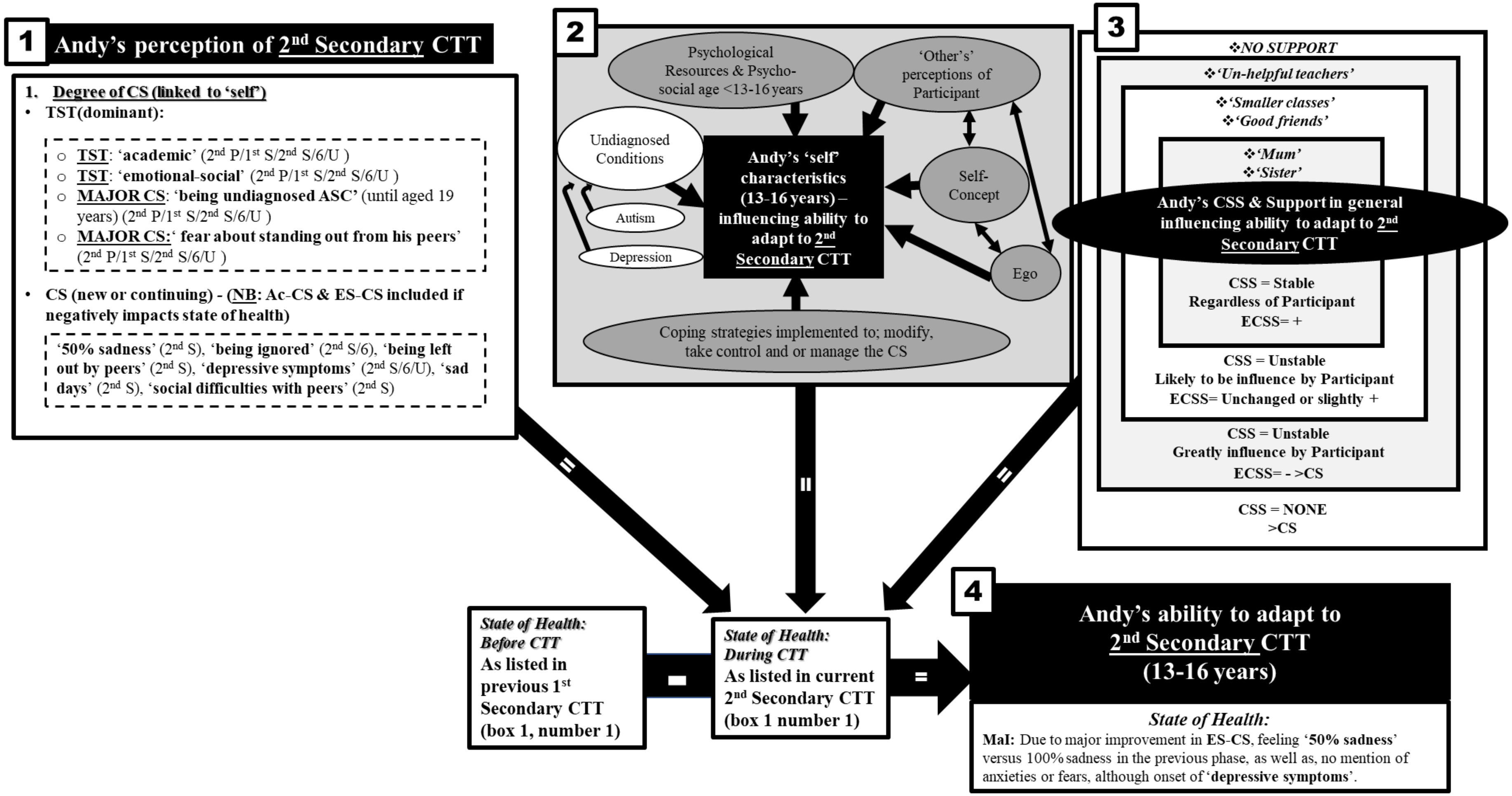


Figure 4.5 (d): Educational transitioning model representing Andy's ability to adapt to the 2nd secondary CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

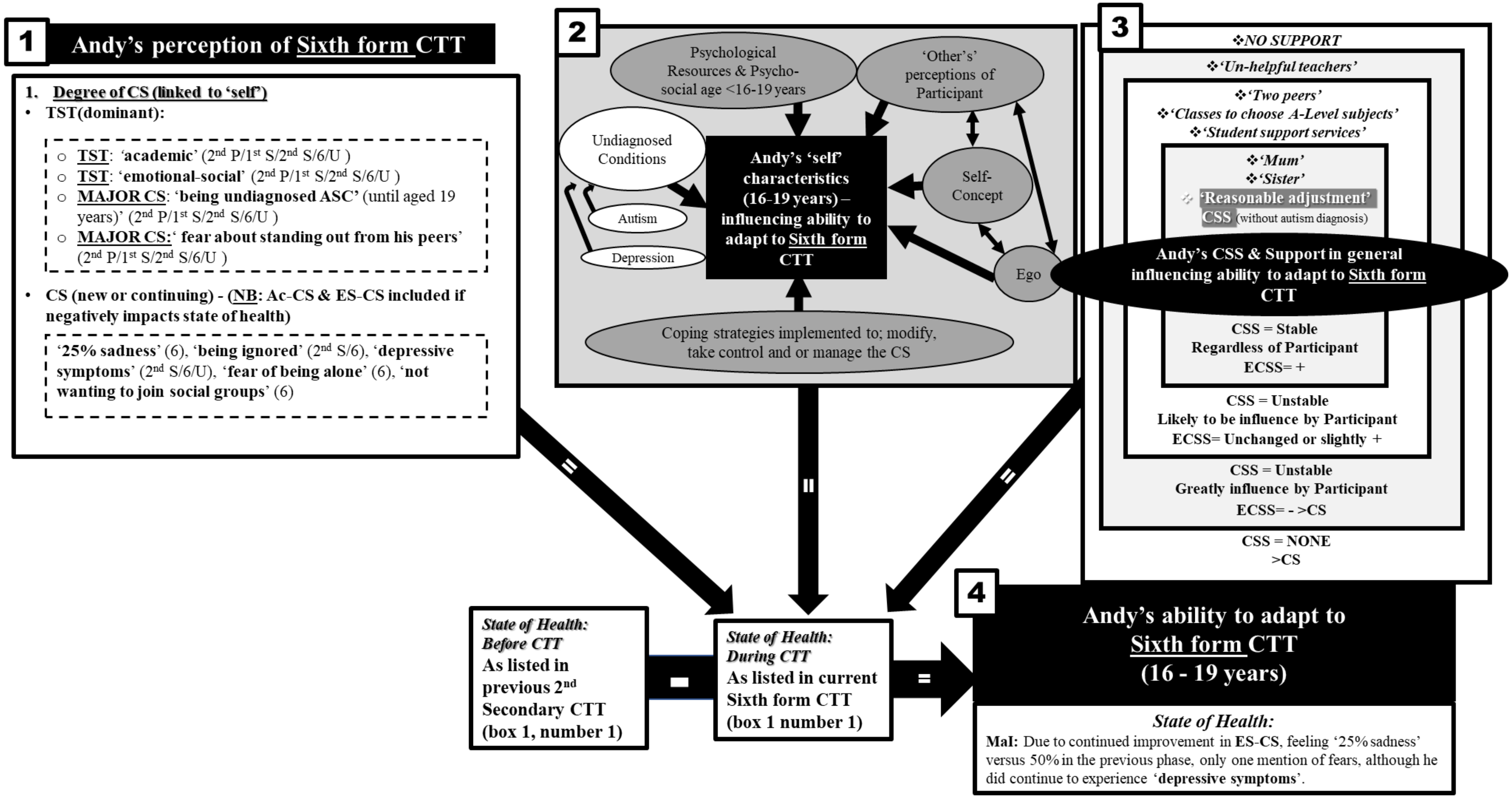
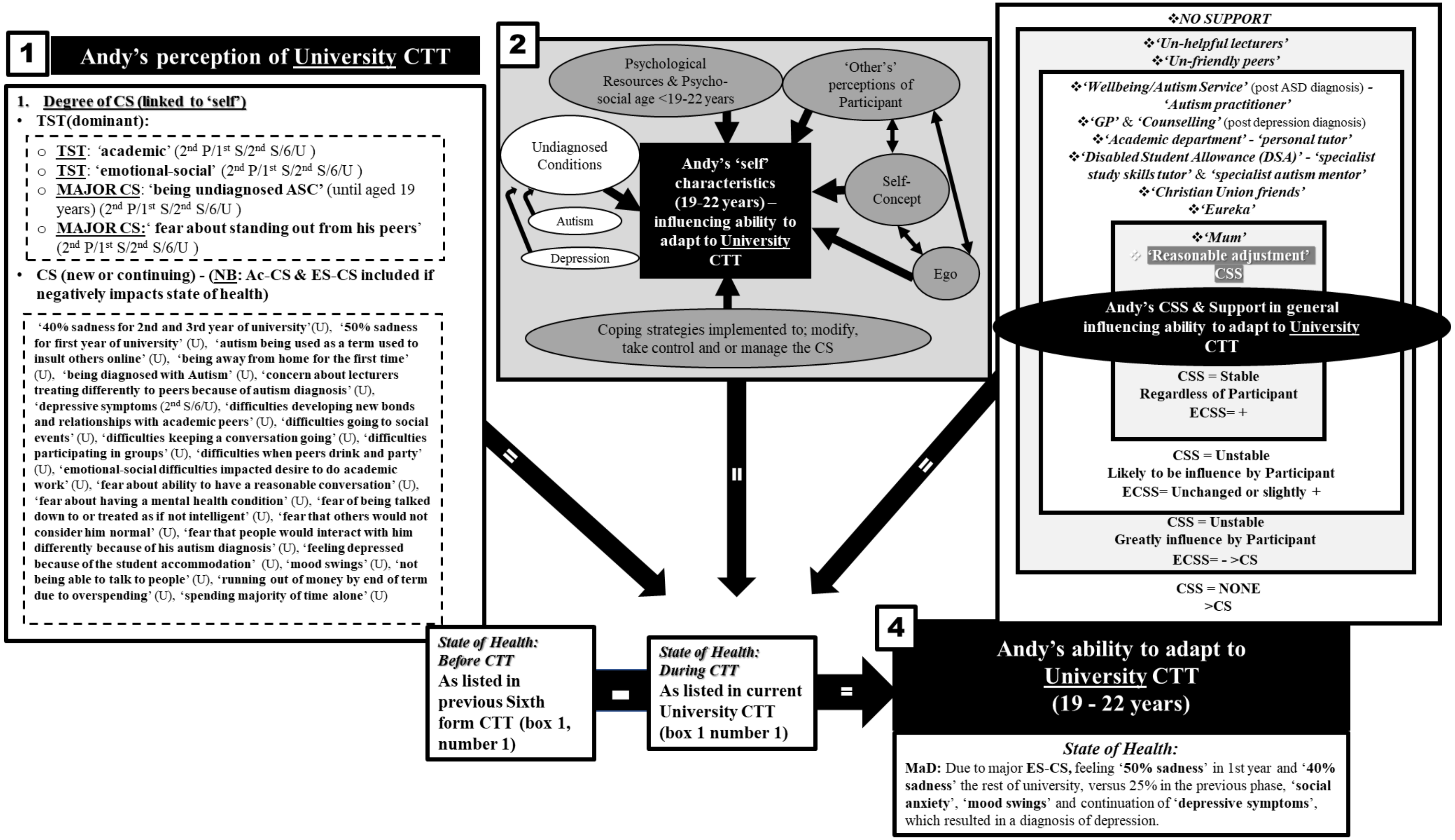


Figure 4.5 (e): Educational transitioning model representing Andy's ability to adapt to the sixth form CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268]

For abbreviations see chapter three, table 3.4.



1. **Degree of CS (linked to 'self')**

- **TST(dominant):**
  - **TST**: **'academic'** (2nd P/1st S/2nd S/6/U)
  - **TST**: **'emotional-social'** (2nd P/1st S/2nd S/6/U)
  - **MAJOR CS**: **'being undiagnosed ASC'** (until aged 19 years) (2nd P/1st S/2nd S/6/U)
  - **MAJOR CS:' fear about standing out from his peers'** (2nd P/1st S/2nd S/6/U)
- **CS (new or continuing) - (NB: Ac-CS & ES-CS included if negatively impacts state of health)**

'40% sadness for 2nd and 3rd year of university'(U), **'50% sadness for first year of university'** (U), **'autism being used as a term used to insult others online'** (U), **'being away from home for the first time'** (U), **'being diagnosed with Autism'** (U), **'concern about lecturers treating differently to peers because of autism diagnosis'** (U), **'depressive symptoms** (2nd S/6/U), **'difficulties developing new bonds and relationships with academic peers'** (U), **'difficulties going to social events'** (U), **'difficulties keeping a conversation going'** (U), **'difficulties participating in groups'** (U), **'difficulties when peers drink and party'** (U), **'emotional-social difficulties impacted desire to do academic work'** (U), **'fear about ability to have a reasonable conversation'** (U), **'fear about having a mental health condition'** (U), **'fear of being talked down to or treated as if not intelligent'** (U), **'fear that others would not consider him normal'** (U), **'fear that people would interact with him differently because of his autism diagnosis'** (U), **'feeling depressed because of the student accommodation'** (U), **'mood swings'** (U), **'not being able to talk to people'** (U), **'running out of money by end of term due to overspending'** (U), **'spending majority of time alone'** (U)

State of Health:

MaD: Due to major **ES-CS,** feeling '**50% sadness**' in 1st year and '**40% sadness**' the rest of university, versus 25% in the previous phase, '**social anxiety**', '**mood swings**' and continuation of '**depressive symptoms**', which resulted in a diagnosis of depression.

Figure 4.5 (f): Educational transitioning model representing Andy's ability to adapt to the university CTT. (1) Degree of CS experienced during CTT, (2) Influence of 'self' characteristics on ability to adapt, (3) CSS support provided, (4) Overall experiences, ability to adapt to CTT and overriding state of health. Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

4.8.11 Procedural step 6

Critical narrative analysis (CNA) considered the functionality of Andy's story, how he was positioned within it, by considering the fabular and sjuzet properties reflecting his; thoughts, feelings, emotions, actions, interactions, achievements, challenges, and the social structure in which his story takes place. CNA identified a critical positioning theme; namely Andy as a 'rational, shy, and gentle' typology.

4.8.11.1 Andy's positioning as a 'rational, shy, and gentle' typology

Throughout Andy's lived experiences shared he continually demonstrated three major core typology characteristics that I (the researcher) felt were so intrinsically intertwined that they all equally formed into his core typology as a 'rational, shy, and gentle' person. Andy demonstrated that he had dominant 'rational' characteristics throughout his 'educational journey' by presenting himself as having a sensible, reasoned, and logical approach, towards all his experiences. Particularly in relation to social interactions, such as was the case during his 1st secondary school CTT when he did not logically understand why when you make two friends, they do not continue to be your friends in a new environment. On several occasions Andy referred to himself as being 'shy' and/or 'nervous', lacking self-advocacy skills, demonstrating throughout that he lacked confidence, particularly in relation to social interactions, feeling uncomfortable with others, not wanting to join social groups, and not wanting to stand out from his peers. There were several occasions where Andy described agitation and/or distress resulting from his social experiences, particularly during his first term at university when he did not want to live with peers who were drinking and partying. Throughout both interviews, experiences shared, Andy exhibited a 'gentle' nature, from his softly spoken intonation to his affable and peaceful presentation. At no point during any negative or distressing experiences shared did he raise his voice or use angry verbal's and/or non-verbals, his predominant reaction was to look down, withdraw into himself, lower his voice, and lean away from the me (the interviewer).

4.8.12 Summary of Andy's ability to adapt to each core transitioning theme

HCA: CTT; 1st primary, 1st secondary, 2nd secondary, sixth form, university.

CCA: TST; academic (Ac), emotional-social (ES).

CFA: Greatest occurrence of major negative tones during secondary CTT. Greatest occurrence of major positive tones during university CTT.

HFA: Indicated a regressive, progressive, regressive, narrative.

HFA & CNA: HFA linguistical analysis and CNA revealed a 'rational, shy, and gentle' evolving typology.

HCA, **CCA**, **CFA**, **HFA**, **combined (table 4.5 (d)):**

2nd Primary CTT, evidences a regressive narrative. Evidence of good support practice took the form of: Stable CSS (regardless of behaviour) was provided by '***Mum***', unstable positive CSS (influenced by behaviour) from a '***smaller learning group***. Data indicated a minor deterioration in state of health evidenced by an increase in some ES-CS, particularly '**social anxiety**'.

1st Secondary CTT, evidences a regressive narrative. This CTT had the greatest overall HFA narrative regression, compared with other CTT. This CTT had the greatest occurrence of CFA major negative tones compared with other CTT. Evidence of good support practice took the form of: Stable CSS continued to be provided by '***Mum***', with additional support from his '***sister***'. Unstable positive CSS from a '***small learning group***', the '***student support services***', and '***friends from previous school***' (until they 'turned their backs on him'). Data indicated a major deterioration in state of health evidenced by a major increase in ES-CS, feeling '**100% sadness**', '**being bullied**', increasing fears, '**low mood**' and sound sensitivities '**when people shouted**'.

2nd Secondary CTT, evidences a progressive narrative. Evidence of good support practice took the form of: Stable CSS continued to be provided by '***Mum***' and his '***sister***', unstable positive CSS from '***smaller classes***' and '***good friends***'. Data indicated a major improvement in state of health evidenced by a major improvement in ES-CS, feeling '**50% sadness**' versus 100% sadness in the previous phase, as well as, no mention of anxieties or fears, although onset of '**depressive symptoms**', implying that he overcame previous CS or that these were considerably reduced.

Sixth form CTT, evidences a progressive narrative. Evidence of good support practice took the form of: Stable CSS continued to be provided by '***Mum***' and his '***sister***', unstable positive CSS from '***two peers***', '***classes to choose A-Level subjects***', and '***student support services***'. '***Reasonable adjustments***' CSS were put in place without an autism diagnosis. Data indicated a major improvement in state of health evidenced by continued major improvement in ES-CS, feeling '**25% sadness**' versus 50% in the previous phase, only one mention of fears, although he did continue to experience '**depressive symptoms**', implying that he overcame previous CS or that these were considerably reduced.

University (BSc) CTT, evidences a regressive narrative. This CTT had the greatest occurrence of CFA major positive tones compared with other CTT. Evidence of good support practice took the form of: Stable CSS continued to be provided by '***Mum***'. Unstable positive CSS from his '***sixth form***' prior to starting university, the '***wellbeing/autism service***' (post autism diagnosis), an '***autism practitioner***', the '***GP***', '***counselling***' (post-depression diagnosis), his '***academic department***', his '***personal tutor***', '***Disabled Student Allowance (DSA)***' (through provision of a '***specialist study skills tutor***' and '***specialist autism mentor***'), '***Christian Union friends***', and through '***Eureka***' (autism social group). '***Reasonable adjustments***' CSS were put in place following his autism diagnosis. Data indicated a major deterioration in state of health evidenced by ongoing ES-CS, feeling '**50% sadness**' in 1st year and '**40% sadness**' the rest of university, versus 25% in the previous sixth form CTT, '**social anxiety**', '**mood swings**' and continuation of '**depressive symptoms**', which resulted in a diagnosis of depression.

Chapter 5: Narrative comparison of participant cases

5.1 Chapter Overview

Narrative case comparisons made in this chapter aim to enable the reader to understand how the general patterns and themes were founded. Upon the completion of individual participant analysis and summary of individual participant findings I (the researcher) inductively theorised across research participants cases with the aim of investigating whether a phenomenon existed, through identification of stable concepts, such as core transitioning themes (CTT), transitioning subthemes (TST), concurrent stressors (CS), and concurrent stressor support (CSS). Participant cases were then compared and discussed in relation to change and transition theory.

5.2 Narrative findings

Narrative findings in this research are not generalisable, or replicable, as they focus on participant specific data, which encapsulated their temporal experiences, over a time continuum, capturing the essence of their particular experience.[252] The findings of this research are not intended to be applied to other settings,[250, 251] however, this research has aimed to produce findings that have the potential to be transferable from one participant's educational transitioning experience to a 'universal transitioning experience' through consideration of relatable participant data to literature and theory.

5.3 Abbreviations, textual highlight coding and key information

Within the main body of the text, tables, and figures: (1) Concurrent stressors (CS) are identified by being written in bold within single inverted commas. Please note, CS included are major '**academic**' (Ac) CS and major or minor '**emotional-social**' (ES) that had an impact on participant state of health only. (2) The names of participants will be written in superscript next to the CS they experienced. (3) Support received for the CS, otherwise known as concurrent stressor support (CSS), are identified by being written in italics and bold, within single inverted commas. (4) From this chapter a 'narrative summary of findings' has been written, and this summary of findings has been made available to participants who requested a copy of it.

5.4 Core transitioning theme correlations, patterns, and relationships among participant data

5.4.1 Primary CTT

The occurrence of concurrent stressors (CS) during the primary core transitioning theme (CTT) are detailed further in appendix 5.1, table (a).

5.4.1.1 EST-CS

There was no mention of ‘**emotional-social transitioning**’ (EST) CS prior to starting this CTT.

5.4.1.2 Ac-CS (major)

Thirteen major ‘**academic**’ (Ac) CS experiences were shared (by participants). Two or more participants experienced CS, ‘**English language**’(Mark, Jane, Andy) and ‘**handwriting**’.(Mark, Jane, Andy)

5.4.1.3 ES-CS (major)

Eight major ‘**emotional-social**’ (ES) CS were shared, ‘**being undiagnosed ASC**’,(Mark, Karen, Jane, Leigh, Andy) ‘**fear about standing out from his peers**’,(Andy) ‘**sensory challenges**’ (SnC)(Jane) and ‘**worrying about others**’.(Leigh)

5.4.1.4 ES-CS (minor)

Twenty-eight minor ES-CS were shared, two or more participants experienced, ‘**friendships**’,(Mark, Karen, Jane) ‘**being bullied**’,(Jane, Leigh) ‘**feeling different to peers**’,(Jane, Leigh) ‘**groups**’(Mark, Andy) and ‘**social difficulties**’.(Mark, Jane)

5.4.1.5 ES-CS (mental health)

Three '**mental health**' (MH) CS experiences were shared by Jane, '**anorexia**', '**anxiety**' and '**trichotillomania**'.

5.4.1.6 Linguistic tone

This CTT saw the greatest occurrence of CFA minor negative-despondent nonverbals for Mark which were suggestive of a negative experience.

5.4.1.7 ES-CSS

In total there was seventeen forms of ES-CSS (evidencing good support practice) provided during this CTT (table 5.1).

Table 5.1: The form of concurrent stressor support provided to participants during the primary CTT.

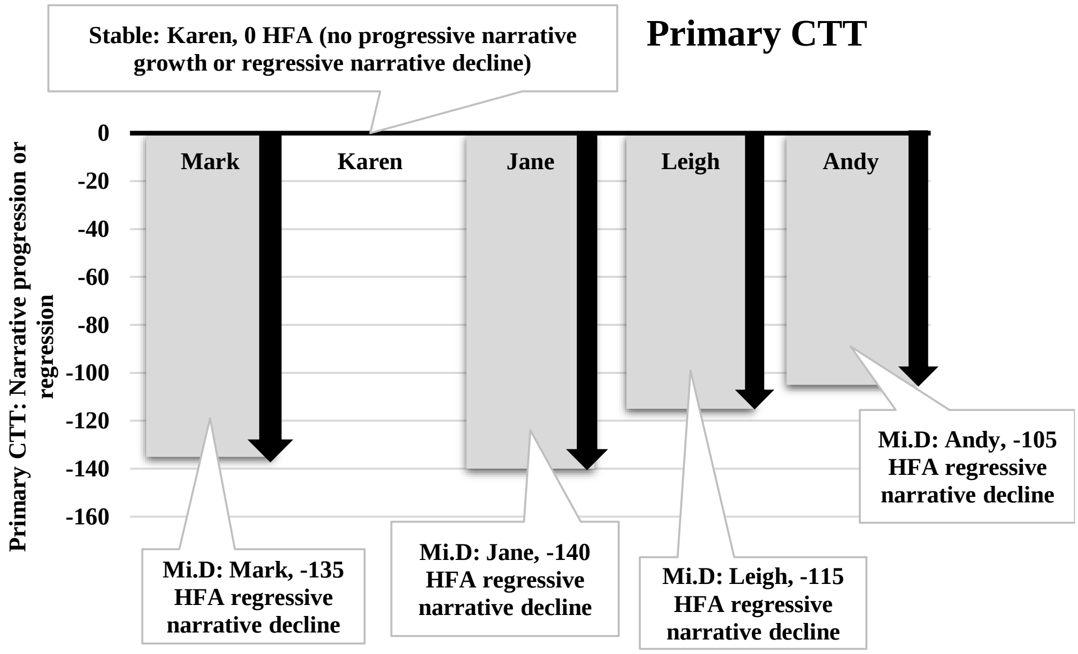
Form of ES concurrent stressor support (ES-CSS) provided	
	'***Mum***'(Mark, Karen, Leigh, Jane, Andy) '***private tutor***'(Mark) '***brother's girlfriend***'(Jane) '***his books***'(Leigh) '***peer friendships***'(Mark, Karen, Jane, Andy) '***small learning group***'(Leigh, Andy) '***helpful teachers***'(Karen)
Total ES-CSS	*f* = 17

5.4.1.8 Narrative progression or regression

As illustrated in figure 5.1 (appendix 5.1 (table (b)), the majority of participants had a regressive narrative(Mark, Jane, Leigh, Andy) during the primary CTT, with the exception of Karen who's narrative was stable.

5.4.1.9 State of health

As illustrated in figure 5.1 (appendix 5.1 (table (b)), the majority of participants experienced a minor deterioration in state of health (MiD),(Mark, Jane, Leigh, Andy) due to increasing Ac-CS(Jane) and ES-CS,(Mark, Jane, Leigh, Andy) with the exception of Karen who’s state of health was stable.



Stable: Karen, 0 HFA (no progressive narrative growth or regressive narrative decline)

Mi.D: Mark, -135 HFA regressive narrative decline

Mi.D: Jane, -140 HFA regressive narrative decline

Mi.D: Leigh, -115 HFA regressive narrative decline

Mi.D: Andy, -105 HFA regressive narrative decline

Figure 5.1: Primary CTT. Correlations, patterns, and relationships among participants’ data in terms of state of health and narrative flow. CTT = core transitioning theme, MiD = minor deterioration in state of health, ES = emotional-social

5.4.2 Secondary CTT

The occurrence of concurrent stressors (CS) during the secondary core transitioning theme (CTT) are detailed further in appendix 5.2 table (a).

5.4.2.1 EST-CS

Prior to starting the secondary CTT nine '**emotional-social transitioning**' (EST) CS experiences were shared '**anxiety about so much change**',$^{\text{(Mark)}}$ '**anxiety about how to make new friends**',$^{\text{(Mark)}}$ '**anxiety about what to expect in new school**',$^{\text{(Mark)}}$ '**apprehensive due to the social upheaval**',$^{\text{(Jane)}}$ '**being forced to have a shower during PE**',$^{\text{(Leigh)}}$ 'c**hanging schools was nerve wrecking**',$^{\text{(Andy 2nd S)}}$ '**fear about the academic jump**',$^{\text{(Andy 1st S)}}$ '**fear of being bullied in new school**' $^{\text{(Andy 1st S)}}$ and '**lack of explicit instructions on how to interact and communicate with peers**'.$^{\text{(Mark)}}$

5.4.2.2 Ac-CS (major)

Eleven major Ac-CS experiences (impacting state of health) were shared, with two or more participants sharing, '**English language**',$^{\text{(Mark, Jane)}}$ '**math**',$^{\text{(Leigh, Andy 2nd S)}}$ and '**time constraints**'.$^{\text{(Mark, Leigh)}}$

5.4.2.3 ES-CS (major)

This CTT had the greatest frequency of nine major ES-CS shared, '**being undiagnosed ASC**',$^{\text{(Mark, Karen, Jane, Leigh, Andy)}}$ '**sensory challenges**' (SnC),$^{\text{(Jane)}}$ '**fear about standing out from his peers**',$^{\text{(Andy)}}$ '**when people shouted**'$^{\text{(Andy 1st S)}}$ and '**worrying about others**'.$^{\text{(Leigh)}}$

5.4.2.4 ES-CS (minor)

This CTT also had the greatest frequency of forty-eight minor ES-CS experiences, two or more participants shared, '**friendships**',(Mark, Karen, Jane, Leigh, Andy) '**being bullied**',(Mark, Jane, Leigh, Andy 1st S) '**social difficulties**',(Mark, Jane, Leigh, Andy) '**feeling different to peers**',(Mark, Karen, Leigh) '**being ignored by peers**',(Leigh, Andy 2nd S) '**being left out by peers**',(Karen, Andy 2nd S) '**not wanting to draw attention to self**'(Mark, Andy) and '**peers who didn't want to learn**'.(Leigh, Andy)

5.4.2.5 ES-CS (mental health)

Eleven mental health CS experiences were shared, '**anorexia**',(Jane) '**anxiety**',(Jane) '**depressive symptoms**',(Andy 2nd S) '**low mood**',(Andy) '**sad days**',(Andy) '**self-harming**',(Jane) '**suicide attempts**',(Jane) '**trichotillomania**',(Jane) '**feeling downtrodden**',(Leigh) '**feeling shame**'(Leigh) and '**feeling sadness**'.(Andy)

5.4.2.6 Linguistic tone

This CTT saw the greatest occurrence of CFA negative nonverbals for all participants such as minor negative-withdrawing and minor negative-worried nonverbal (suggestive of a negative experience) for Mark, minor negative-twisting hands (suggestive of negative experience) for Karen, minor negative-disappointed, major negative-angry, major negative (in general) for Jane, and major negative overall for Leigh and Andy.

5.4.2.7 EST-CSS and ES-CSS

In total there was four forms of EST-CSS and twenty forms of ES-CSS (evidencing good support practice) provided to participants during this secondary CTT (table 5.2).

Table 5.2: The form of emotional-social concurrent stressor support and concurrent stressor support provided to participants during the secondary CTT.

Form of emotional-social transitioning concurrent stressor support (EST-CSS) provided	
	‘***secondary school***’ induction/transition event(Mark, Karen) ‘***primary school***’ provided Karen with a book that explained what secondary school would be like. ‘***SEN department***’ (specialist educational needs unit) was provided to Jane prior to starting and during the first few weeks.
Total EST-CSS	*f* = 4

Form of ES concurrent stressor support (ES-CSS) provided	
	‘***Mum***’(Mark, Karen, Jane, Leigh, Andy) ‘***Dad***’(Karen, Leigh) ‘***private tutor***’(Mark) ‘***sister***’(Andy) ‘***his books***’(Leigh) ‘***peer friendships***’(Mark, Karen, Jane, Leigh, Andy) ‘***smaller learning group***’(Andy) ‘***helpful teachers***’(Karen, Jane, Leigh) ‘***child and adolescent mental health service (CAMHS)***’(Jane)
Total ES-CSS	*f* = 20

5.4.2.8 Narrative progression or regression

As illustrated in figure 5.2 (appendix 5.2 (table (b)), all participants (including Andy during his 1st secondary CTT) had a regressive narrative during the secondary CTT.

5.4.2.9 State of health

As illustrated in figure 5.2 (appendix 5.2 (table (b)), all participants (including Andy during his 1st secondary CTT) experienced a major deterioration in state of health (MaD),(Mark, Karen, Jane, Leigh, Andy) due to all experiencing increasing Ac-CS and ES-CS.

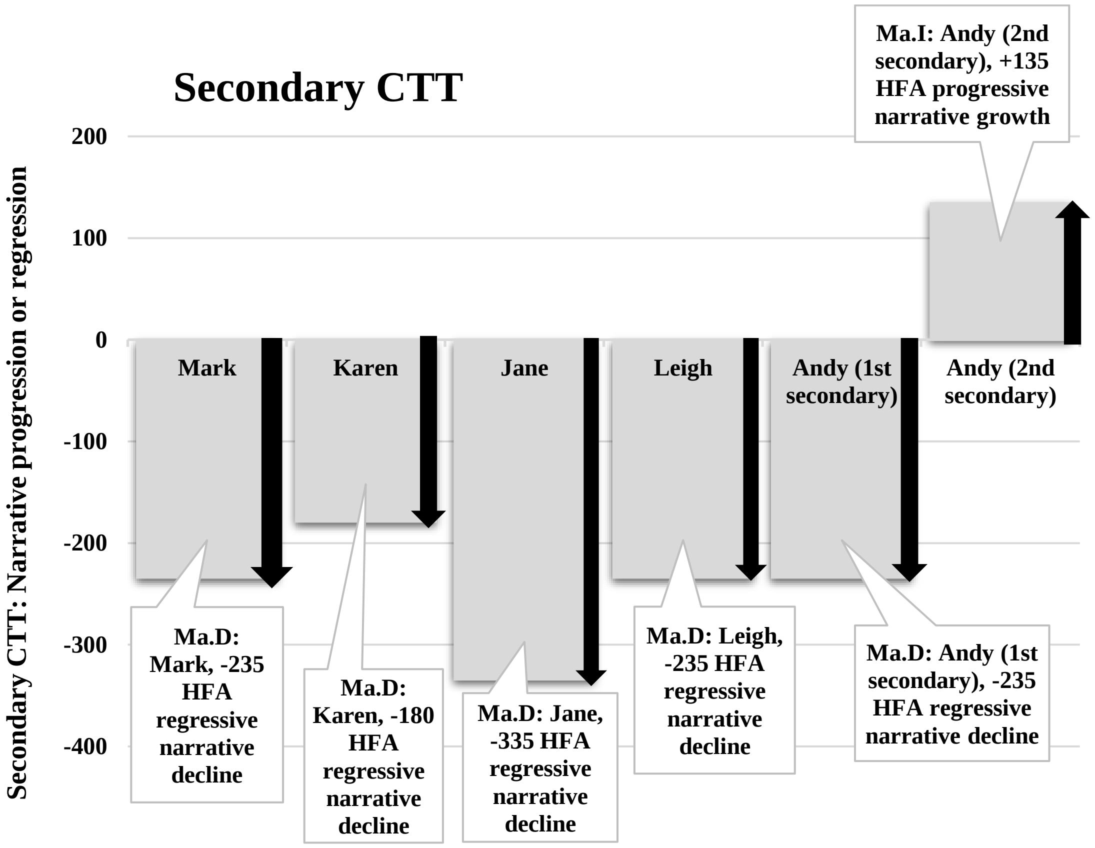


Figure 5.2: Secondary CTT. Correlations, patterns, and relationships among participants' data in terms of state of health and narrative flow. CTT = core transitioning theme, MaD = major deterioration in state of health, MaI = major improvement in state of health, ES = emotional-social

Please note that Andy had a considerable reduction in his Ac-CS and ES-CS in his 2nd secondary CTT, resulting in a progressive narrative and a major improvement in his state of health, implying that he overcame previous CS or that these were considerably reduced, with some CS remaining (as noted in appendix 5.2 (b)).

5.4.3 Sixth form CTT

The occurrence of concurrent stressors (CS) during the sixth form CTT are detailed further in appendix 5.3 table (a).

5.4.3.1 EST-CS

During this CTT three '**emotional-social transitioning**' (EST) CS experiences were shared, '**fear about the long journey she had to make to sixth form**',$^{\text{(Karen)}}$ '**fear that she would not get along with her sixth form peers**'$^{\text{(Karen)}}$ and '**struggled to readapt to sixth form college**'.$^{\text{(Jane)}}$

5.4.3.2 Ac-CS (major)

Eight major Ac-CS experiences (impacting state of health) were shared, two or more participants experienced, '**increase academic demands**',$^{\text{(Jane, Leigh, Andy)}}$ '**A-Level exams**'$^{\text{(Mark, Leigh)}}$ and '**time**'.$^{\text{(Leigh, Andy)}}$

5.4.3.3 ES-CS (major)

Six major ES-CS experiences were shared, '**being undiagnosed ASC**',$^{\text{(Mark, Karen, Andy)}}$ '**fear about standing out from his peers**',$^{\text{(Andy)}}$ '**sensory challenges**' (SnC)$^{\text{(Jane)}}$ and '**worrying about others**'.$^{\text{(Leigh)}}$

5.4.3.4 ES-CS (minor)

Seventeen minor ES-CS experiences were shared, with only '**stigma of having ASC**'$^{\text{(Mark, Jane)}}$ CS being shared by two or more participants.

5.4.3.5 ES-CS (mental health)

Six ‘**mental health**’ (MH) CS experiences were shared, ‘**anorexia**’,(Jane) ‘**anxiety**’,(Jane) ‘**depressive symptoms**’,(Andy) ‘**sadness**’,(Andy) ‘**self-harming**’(Jane) and ‘**stress**’.(Jane)

5.4.3.6 Linguistic tone

This CTT saw the greatest occurrence of CFA major positive nonverbals for Jane.

5.4.3.7 EST-CSS and ES-CSS

In total there was four forms of EST-CSS and twenty-one forms of ES-CSS provided (evidencing good support practice) during this sixth form CTT (table 5.3).

Table 5.3: The form of emotional-social concurrent stressor support and concurrent stressor support provided to participants during the sixth form CTT.

Form of emotional-social transitioning concurrent stressor support (EST-CSS) provided	
	‘***sixth form college***’(Karen) ‘***Mum***’(Karen) ‘***Dad***’(Karen) ‘***sixth form college***’(Jane)
Total EST-CSS	*f* = 4

Form of ES concurrent stressor support (ES-CSS) provided	
	‘***Mum***’(Mark, Karen, Jane, Leigh, Andy) ‘***Dad***’(Karen, Leigh) ‘***private tutor***’(Mark) ‘***sister***’ (Andy) ‘***autism centre manager***’ (Jane) ‘***his books***’ (Leigh) ‘***peer friendships***’(Mark, Karen, Jane, Andy) ‘***helpful teachers***’(Karen, Jane, Leigh) ‘***sixth form tutor***’ (Jane, Leigh) ‘***student support services***’(Andy)
Total ES-CSS	*f* = 21

5.4.3.8 Narrative progression or regression

As illustrated in figure 5.3 (appendix 5.3 (table (b)), all participants had a progressive narrative, during the sixth form CTT.

5.4.3.9 State of health

As illustrated in figure 5.3 (appendix 5.3 (table (b)), all participants experienced a major improvement in state of health (MaI),(Mark, Karen, Jane, Leigh, Andy) due to a reduction in their Ac-CS and ES-CS.

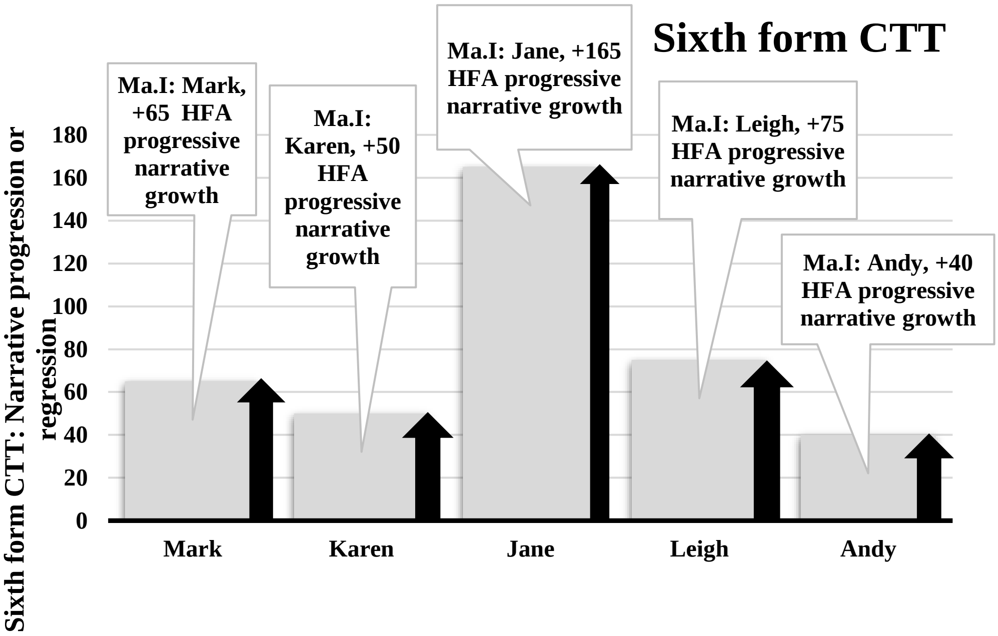


Figure 5.3: Sixth form CTT. Correlations, patterns, and relationships among participants' data in terms of state of health and narrative flow. CTT = core transitioning theme, MaI = major improvement in state of health, ES = emotional-social

5.4.4 University (BSc) CTT

The occurrence of concurrent stressors (CS) during the university (BSc) CTT are detailed further in appendix 5.4 table (a).

5.4.4.1 EST-CS

During this CTT there was thirteen '**emotional-social transitioning**' (EST) CS experiences shared. '**Fear about moving away from home**',(Karen) '**fear of being alone**',(Andy) '**fear of change**',(Karen) '**feeling homesick**',(Karen) '**guilt about not getting used to university life as quickly as she thought she should**',(Karen) '**having to meet a whole load of new people**',(Mark) '**having to visit other universities with his parents even though he had** '**already decided due to his chosen universities autistic CSS**',(Mark) '**not being able to tell parents that he wanted to go to his chosen** '**university due to its autistic CSS**',(Mark) '**social difficulties with peers**'(Leigh) (worried would continue), '**the uncertainty ahead of him**',(Mark) '**uncertainty about whether she wanted to go to university or not**',(Karen) '**whether she had sufficient independent living skills to live alone**'(Karen) and '**worried about being rejected by his peers and that no one would like him**'(Mark)

5.4.4.2 Ac-CS (major)

This CTT also had the greatest frequency of fifteen major Ac-CS experiences (impacting state of health) shared, two or more participants experienced, '**increase academic demands**',(Jane, Leigh, Andy) '**A-Level exams**'(Mark, Leigh) and '**time**'.(Leigh, Andy)

5.4.4.3 ES-CS (major)

Five major ES-CS experiences were shared, '**being undiagnosed ASC**',(Karen, Andy) Andy was diagnosed during his first year and Karen at the end of her degree, '**fear about standing out from his peers**',(Andy) '**sensory challenges**' (SnC)(Jane) and '**worrying about others**'.(Leigh)

5.4.4.4 ES-CS (minor)

Thirty-eight minor ES-CS were shared, two or more participants experienced, '**friendships**',$^{\text{(Mark, Karen, Jane, Andy)}}$ '**changes**',$^{\text{(Mark, Karen, Jane)}}$ '**living independently**',$^{\text{(Karen, Jane, Andy)}}$ '**social difficulties**',$^{\text{(Mark, Jane, Andy)}}$ '**disclosing ASC**',$^{\text{(Mark, Andy)}}$ '**fear of failing**',$^{\text{(Mark, Karen)}}$ '**groups**'$^{\text{(Karen, Andy)}}$ and '**loneliness**'.$^{\text{(Jane, Andy)}}$

5.4.4.5 ES-CS (mental health)

This CTT had the greatest frequency of 15 '**mental health**' (MH) CS ranging from, '**stress**',$^{\text{(Karen, Andy)}}$ '**anxiety**',$^{\text{(Jane)}}$ '**anxiety about world affairs**',$^{\text{(Leigh)}}$ '**depressive symptoms**',$^{\text{(Andy)}}$ '**emotional-social problems impacting ability to do work**',$^{\text{(Andy)}}$ '**fear about having a mental health condition**',$^{\text{(Andy)}}$ '**fear of academic level and amount of work**',$^{\text{(Andy)}}$ '**fear of being talked down to or treated as if not intelligent**',$^{\text{(Andy)}}$ '**fear that others would interact with him differently because of his autism diagnosis**',$^{\text{(Andy)}}$ '**fear that others would not consider him normal**',$^{\text{(Andy)}}$ '**fear that she couldn't finish her degree**',$^{\text{(Karen)}}$ '**mood swings**',$^{\text{(Andy)}}$ '**phobias**'$^{\text{(Leigh)}}$ and '**sadness**'.$^{\text{(Andy)}}$

5.4.4.6 Linguistic tone

This CTT saw the greatest occurrence of CFA major positive nonverbals for Mark, Karen, Leigh, and Andy.

5.4.4.7 EST-CSS and ES-CSS

This CTT had the greatest frequency of sixteen EST-CSS and thirty-four forms of ES-CSS provided (evidencing good support practice) during this university (BSc) CTT (table 5.4).

Table 5.4: The form of emotional-social concurrent stressor support and concurrent stressor support provided to participants during the university (BSc) CTT.

Form of emotional-social transitioning concurrent stressor support (EST-CSS) provided	
	‘***sixth form***’(Mark, Karen, Jane, Leigh, Andy)
	‘***university***’(Mark, Karen, Jane) (university open day for all, two-day induction Mark and Jane)
	‘***autism practitioner***’(Mark, Jane)
	‘***parents***’(Karen, Jane, Leigh)
	‘***sixth form teachers***’(Leigh) (with academic preparation)
	‘***Durrell wildlife trust***’(Leigh) (with his choice of university)
	From a ‘***friend***’(Leigh) (already at his chosen university)
Total EST-CSS	*f* = 16

Form of ES concurrent stressor support (ES-CSS) provided	
	‘***Mum***’(Mark, Karen, Jane, Leigh, Andy)
	‘***Dad***’(Karen, Leigh)
	‘***private tutor***’(Mark)
	‘***sister***’(Andy)
	‘***boyfriend***’(Jane)
	‘***his book***’(Leigh)
	‘***peer friendships***’(Karen, Leigh)
	‘***friend from home***’(Jane)
	‘***autism social group called eureka***’(Mark, Jane, Andy)
	‘***Christian union***’(Andy)
	‘***disability team***’(Leigh)
	‘***specialist autism practitioners***’(Mark, Jane, Andy)
	‘***autism mentors***’(Mark, Jane, Andy)
	‘***autism tutors***’(Mark, Jane, Andy)
	‘***counselling***’(Andy)
	‘***academic department***’(Andy)
	‘***personal tutor***’(Andy)
	‘***lecturers***’(Karen, Leigh)
	‘***exams office***’(Andy)
Total ES-CSS	*f* = 34

5.4.4.8 Narrative progression or regression

As illustrated in figure 5.4 (appendix 5.4 (table (b)), Mark, Karen, Jane, had a progressive narrative, and Leigh, Andy, a regressive narrative, during the university (BSc) CTT.

5.4.4.9 State of health

As illustrated in figure 5.4 (appendix 5.4 (table (b)), Mark and Jane experienced a major improvement in state of health (MaI), Karen a minor improvement in state of health

(MiI), due to continued reduction in Ac-CS and ES-CS. Leigh experienced a minor deterioration in state of health (MiD), due to new ES-CS, OCD related symptoms and phobias. Andy experienced a major deterioration in state of health (MaD), due to major ES-CS, feeling ‘50%’ sadness in 1st year and ‘40%’ sadness the rest of university, versus ‘25%’ in the previous sixth form CTT, several major Ac-CS (impacting state of health) and social fears, continuation of depressive symptoms, resulting in diagnosis of depression, and ongoing mood swings.

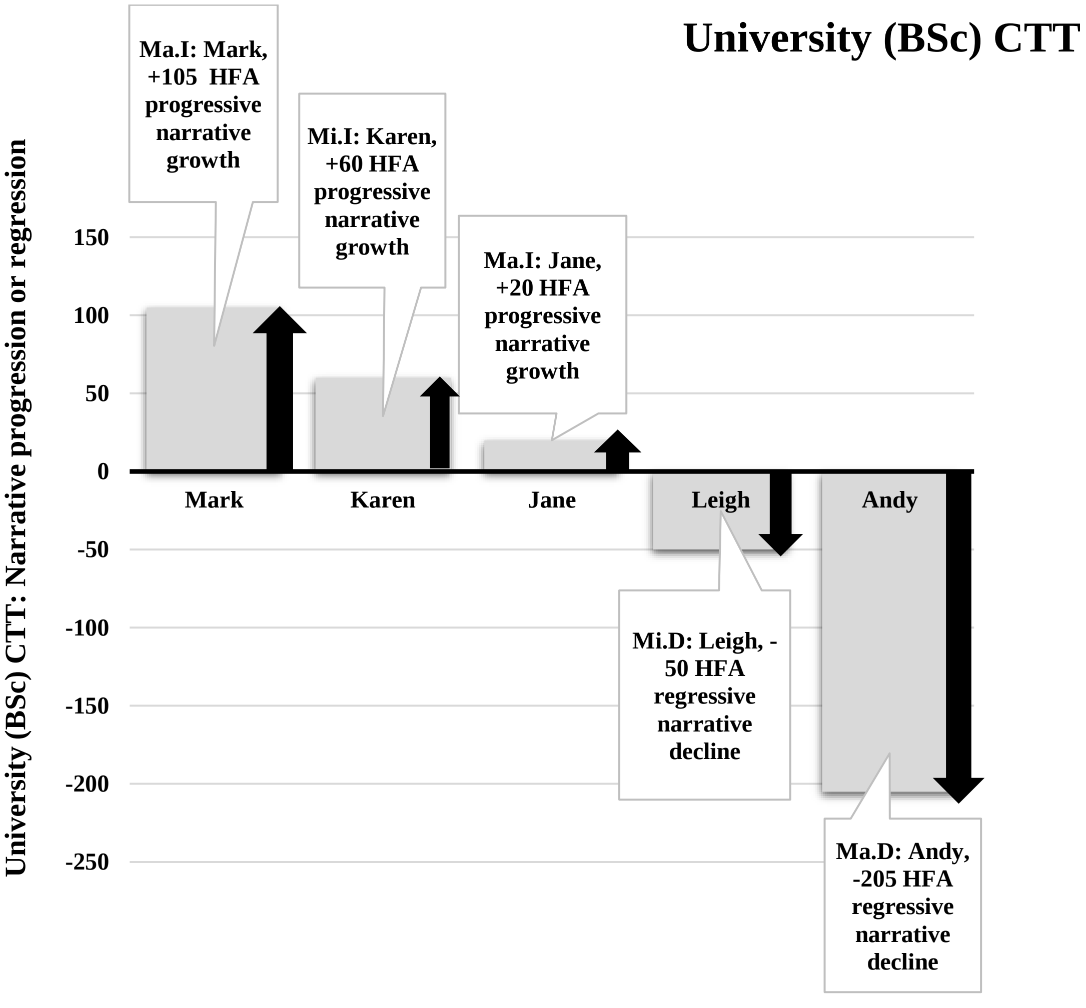


Figure 5.4: University (BSc) CTT. Correlations, patterns, and relationships among participants’ data in terms of state of health and narrative flow. CTT = core transitioning theme, MaI = major improvement in state of health, MiI - minor improvement in state of health, MiD = minor deterioration in state of health, MaD = major deterioration in state of health, ES = emotional-social

5.4.5 University (MSc) CTT

The occurrence of concurrent stressors (CS) during the university (MSc) CTT are detailed further in appendix 5.5.

5.4.5.1 EST-CS

During this CTT Karen had five ‘**emotional-social transitioning**’ (EST) CS, ‘**fear about living independently**’,$^{(Karen)}$ ‘**fear about living with new people**’,$^{(Karen)}$ ‘**fear about returning to academic studies**’,$^{(Karen)}$ ‘**greater CS starting her MSc compared with what she felt starting her BSc**’$^{(Karen)}$ and ‘**worried that she wouldn’t be able to keep up with the course and do the exams**’.$^{(Karen)}$

5.4.5.2 Ac-CS (major)

Karen and Leigh did not appear to have any major ‘**academic**’ (Ac) CS during the university (MSc) CTT. Minor Ac-CS (not impacting state of health) took the form of ‘**increase academic demands**’$^{(Karen, Leigh)}$ CS, and ‘**time**’ CS continued for Leigh.

5.4.5.3 ES-CS (major)

Karen and Leigh did not appear to have continuing major ‘**emotional-social**’ (ES) CS during the university (MSc) CTT.

5.4.5.4 ES-CS (minor)

Some minor ES-CS continued that did not give the impression of impacting Karen’s state of health during this CTT, such as ‘**being undiagnosed**’ with dyspraxia CS, ‘**changes**’ CS, ‘**disclosing ASC**’ CS, ‘**friendships**’ CS, ‘**living independently**’ CS, ‘**living with new people**’ CS, ‘**returning to academic studies**’ CS, ‘**that the university might think less of her due to her ASC diagnosis**’ CS, ‘**that the**

university might think she shouldn't be in university due to her ASC diagnosis' CS and '**stress**' CS. Leigh had continuing minor ES-CS '**being undiagnosed**' with OCD.

5.4.5.5 ES-CS (mental health)

Karen also mentioned '**mental health**' (MH) CS '**fear of failing academically**'(Karen) which did not appear to impact her state of health. Leigh had continuing MH-CS '**worrying about others**' and '**phobias**', but these did not give the impression of impacting his state of health.

5.4.5.6 EST-CSS and ES-CSS

In terms of EST-CSS (evidencing good support practice), this was provided to Karen by her university, through an '***open day and an autism specific 2-day induction event***'. Karen and Leigh were provided with stable ES-CSS (evidencing good support practice), regardless of their behaviour, from their '***Mum***' and '***Dad***'. Leigh continued to state that he received stable CSS from '***his books***'. Unstable (positive) CSS continued to be provided to Karen and Leigh through '***peer friendships***' and '***friendships from an autism social group***' called Eureka. The '***wellbeing ASC service***' and their '***lecturers***', provided them both with CSS, and in addition to this Karen received '***autism mentor***' CSS, through disabled student allowance (DSA).

5.4.5.7 Narrative progression or regression

As illustrated in figure 5.5 (appendix 5.5), Karen experienced progressive narrative growth and Leigh a stable narrative, during the university (MSc) CTT.

5.4.5.8 State of health

As illustrated in figure 5.5 (appendix 5.5), Karen experienced a major improvement in state of health (MaI), due to no mention of ongoing ES-CS. Leigh experienced a stable state of health due to no new ES-CS, OCD related symptoms and phobias.

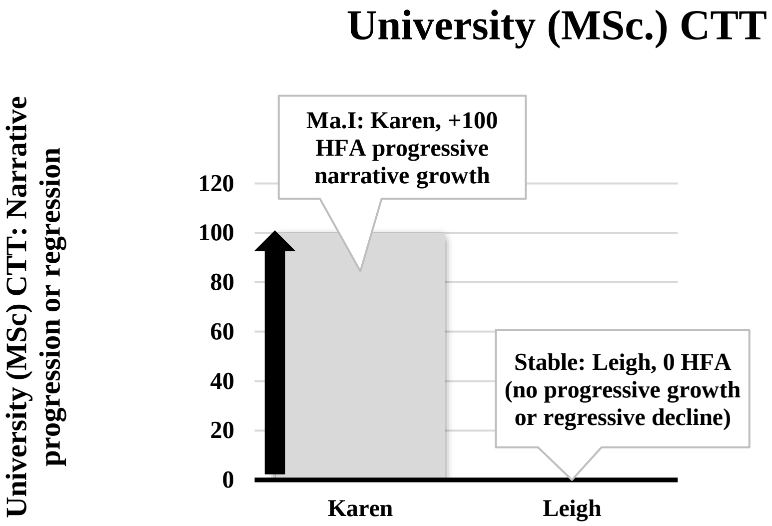


Figure 5.5: University (MSc) CTT. Correlations, patterns, and relationships among participants’ data in terms of state of health and narrative flow. CTT = core transitioning theme, MaI = major improvement in state of health, ES = emotional-social

5.5 Summary of core transitioning theme correlations, patterns and relationships amongst participants

Throughout all core transitioning themes (CTT), the complete educational journey, all participants experienced concurrent stressors (CS) that impacted their state of health which were categorised as, major Ac-CS (which had an impact on state of health), major ES-CS and minor ES-CS which included MH-CS. The most frequent overall CS, based on number of participants experiencing CS in every CTT, was major ES-CS ‘**being undiagnosed ASC**’ (*f=15*), minor ES-CS ‘**friendship**’ (*f=13*), minor ES-CS ‘**social difficulties**’ CS (*f=12*) and major Ac-CS ‘**time**’ (*f=10*).

(1) The secondary CTT had the greatest frequency of total CS (*f=88*), in the context of all participants’ data and all CTTs, relating to their EST-CS, major Ac-CS, major ES-CS, minor ES-CS including MH-CS. This CTT had the greatest frequency of major ES-CS (*f=9*) and minor ES-CS (*f=48*). This CTT also had the greatest occurrence of all participants using the most frequent amount of negative nonverbals when discussing their secondary experiences (including Andy during his 1st secondary CTT and excluding Andy during his 2nd secondary CTT). All participants during this CTT had a major deterioration in state of health (MaD) (including Andy during his 1st secondary CTT and excluding Andy during his 2nd secondary CTT).

(2) The university (BSc) CTT had the next greatest frequency of CS (*f=87*), in the context of all participants’ data and all CTTs, relating to their EST-CS, major Ac-CS, major ES-CS, minor ES-CS including MH-CS. This CTT had the greatest frequency of EST-CS (*f=14*), major Ac-CS (*f=15*) and MH-CS (*f=15*). This CTT had the greatest occurrence of positive nonverbals for Mark, Karen, Leigh, and Andy, when discussing their university (BSc) experiences. This CTT also had the greatest frequency of concurrent stressor support (CSS) (evidencing good support practice) (*f=34* types of CSS) for all participants during this CTT (this figure does not include EST-CSS).

(3) The sixth form CTT saw the least frequency of CS (*f=40*), in the context of all participant data and all CTTs, relating to EST-CS, major Ac-CS, major ES-CS, minor ES-CS including MH-CS. This CTT had the least frequency of minor ES-CS

(*f=17*). This CTT saw the greatest occurrence of positive nonverbals for Jane, discussing her sixth form experiences. This CTT also had the greatest occurrence of a major improvement in state of health (MaI) for Mark, Karen, Jane, Leigh and Andy. The CTT had the next greatest frequency of concurrent stressor support (CSS) (evidencing good support practice) (*f=21* types) for all participants during this CTT (this figure does not include EST-CSS).

5.6 Narrative comparison of participant cases in relation to change and transition theory

5.6.1 Hierarchy of needs

All participants evidenced transitioning barriers which influenced their ‘hierarchy of needs’ and the barriers that they needed to overcome in order to reach their ‘full potential’ academically, emotionally, socially and in terms of their independence. Figure 5.6 is a visual adaption of Maslow’s[257] model, representing the transitioning barriers faced and/or overcome by participants during their educational journey. Many of the barriers experienced by participants mirrored findings in related literature, as noted in this section.

The physiological-barriers that were observed included ‘**sensory challenges**’ (SnC) $^{\text{(Mark, Jane, Andy)}}$ and ‘**eating disorders**’.$^{\text{(Jane)}}$ Safety-barriers, when they did not feel safe in their educational environment, occurred due to ‘**sensory challenges**’,$^{\text{(Mark, Jane, Andy)}}$ ‘**being bullied**’$^{\text{(Mark, Karen, Jane, Leigh, Andy)}}$ and/or ‘**discriminated against**’.$^{\text{(Jane)}}$[192, 193, 197, 204, 208, 211, 215-217, 224, 226] Belonging-barriers, when they lacked a sense of belonging,[193, 215, 217] often stemmed from their ‘**emotional-social**’ CS, particularly when rejected by their peers$^{\text{(Mark, Karen, Jane, Leigh, Andy)}}$ and/or continued discrimination.$^{\text{(Jane)}}$ Self-barriers,[193, 215, 217] tended to appear because of autism related CS, possible negative sense of self.$^{\text{(Mark, Karen, Jane, Leigh, Andy)}}$ These were shaped by their previous experiences, lack of social acceptance, bullying, and so on.

The final step in the hierarchy of needs model[257] is the participant’s ability to reach self-actualization, to achieve their full potential academically, emotionally-socially, and in terms of independence. To be able to achieve self-actualization, participants needed to overcome the aforementioned barriers. Throughout all participant narratives, they demonstrated times when they were able to reach their full potential in some areas, however in reality, their educational journey was not a simplistic process due to the nature of their condition(s), bio-ecological and PPCT elements, and the vast array of concurrent stressors/barriers and challenges facing them.[255, 256]

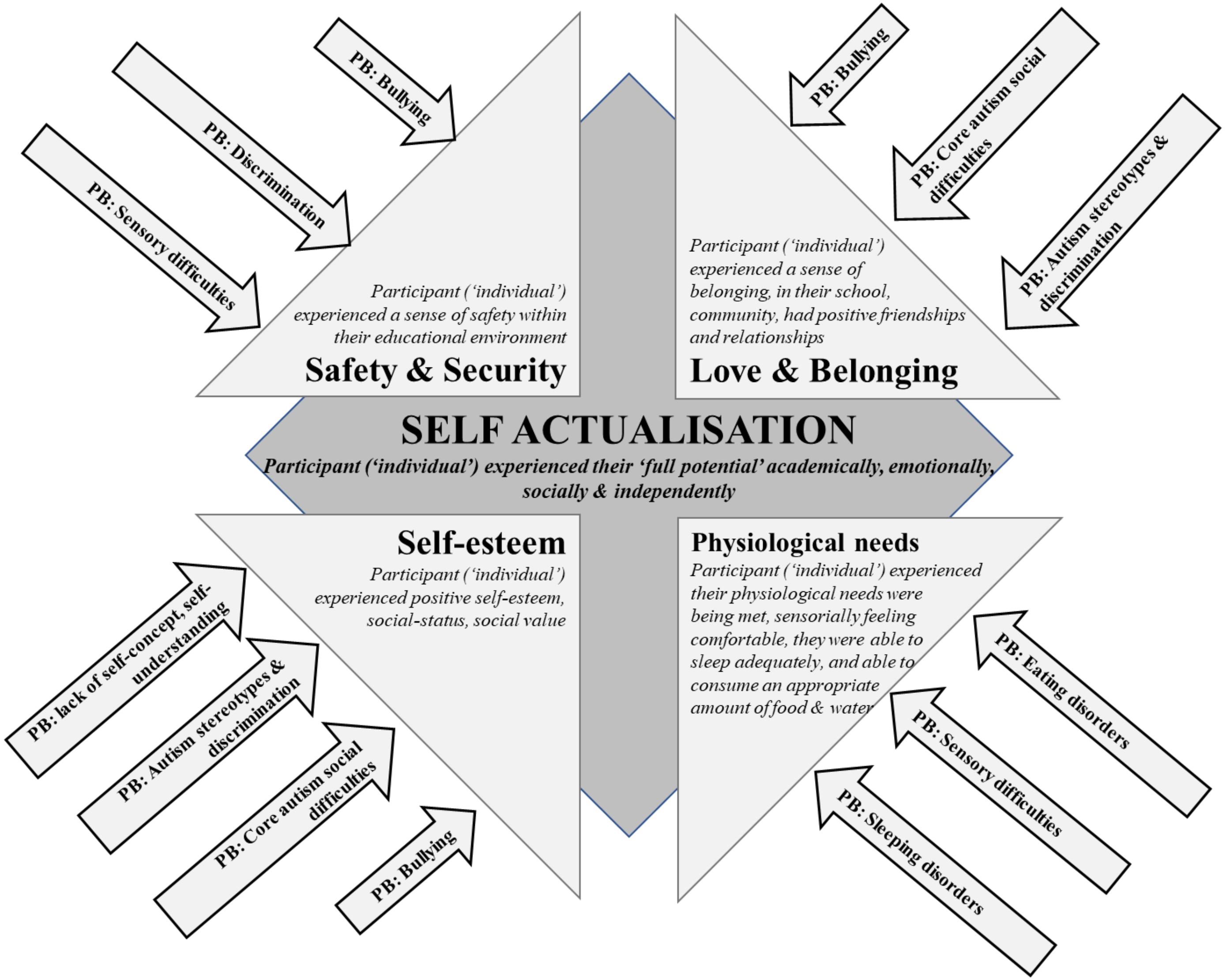


Figure 5.6: Participants and individuals, their educational transitioning experiences in relation to their 'hierarchy of needs'. A visual representation adapted from: Maslow (1943) 'Hierarchy of needs model'.[257] 'Individual' = Individual with autism (in literature), PB = potential barrier

5.6.2 Bio-ecological and PPCT model

The bio-ecological and PPCT theoretical models[255, 256] were used as a framework, enabling me to consider the multitudinous factors that influenced participants transitioning experiences, and ultimate ability to reach their full potential, as evidenced in figure 5.7. Throughout all participants' narratives, it was evident that their ability to perform at their best and develop to the fullest was greatly influenced by their experiences and in particular, their self-concept in relation to autism.

Results demonstrated that day-to-day interpersonal interactions (the ***microsystem***) were greatly influenced by the experiences that they had with their support network. These support networks included '***Mum***',(Mark, Karen, Jane, Leigh, Andy) '***Dad***',(Karen, Jane, Leigh) '***sister***',(Andy) '***close family friends***', (Jane) '***a small number of friends***',(Mark, Karen, Jane, Leigh, Andy) '***supportive teachers/tutors/lecturers***',(Mark, Karen, Jane, Leigh, Andy) '***private tutor***',(Mark) and '***autism specific services***'.(Mark, Karen, Jane, Leigh, Andy)

All narratives detailed the influence that interrelationships between settings had on participants (the ***mesosystem***). Jane's narrative demonstrated the influence that her extended family had on her self-concept, how their perception that she was "*mad*",(PFM203/00:30:46) resulted in lack of understanding and familiar CSS (with the exception of CSS provided by '***mum***'). All participants' narratives highlighted the importance of proactive interrelationships between settings such as between the undiagnosed child, who is displaying autistic characteristics, the family, the school, and the diagnostic services. It was evident that when participants faced delays in being diagnosed with autism (and other related conditions), that this resulted in an increase in their experiences of concurrent stressors (CS) and, usually, a lack of concurrent stressor support (CSS) for such stressors. It was evident that lengthy delays, when being referred by school and/or medical professional,(Mark, Karen, Jane, Leigh, Andy) greatly influenced experiences and participants' self-understanding.

Participants' narratives demonstrated how external factors (the ***exosystem***) influenced their experiences, such as when schools were unable to provide specialised CSS due to lack of diagnosis and/or funding,(Jane) when delays in referral for assessment occurred and/or when there were delays, or it was not possible, for an educational provider to put reasonable adjustments in place for them.(Mark, Karen, Jane, Leigh, Andy)

Narratives highlighted how participants' experiences were shaped by wider societal views, particularly others stereotypical views about autism (the ***macrosystem***). Societal views appeared to influence how others behaved towards participants, likely to be the reason why they were bullied by their peers$^{(\text{Mark, Jane, Leigh, Andy})}$ and/or discriminated against by their teachers.$^{(\text{Jane})}$ All participants gave examples of how their experiences, and views of autism, were negatively influenced by societies stereotypical portrayals of autism. Their narratives evidenced their concerns, and/or their parents' concerns, about someone having an autistic label, demonstrating how societal views were likely to be a key factor in their assessment being delayed.$^{(\text{Mark, Karen, Jane, Leigh, Andy})}$ Participants also voiced concerns that being diagnosed would result in them being treated differently by others, which appeared to not only hinder assessment$^{(\text{Mark, Karen, Jane, Andy})}$ but also them disclosing and accessing support once diagnosed.$^{(\text{Mark, Andy})}$

Finally, the complete narrative (the ***chronosystem***) illustrated, the contextual environmental influencers that were presented in participant results such as, major events, or changes, and how these influenced their educational journey at varying time points. For example, Jane's narrative clearly highlighted the part played by the major event of a suicide attempt, in being assessed, diagnosed, and provided with appropriate CSS.

The later elements of '***process-person-context-time***' (PPCT) have been included in figure 5.7 to highlight the additional factors that influenced participants' experiences. It was clear in their results that all transitions were influenced by '***process***' factors such as social interactions and physical interactions, within the context of their micro-, meso-, exo-, macro- and chrono- settings. Results demonstrated that every participant was unique in terms of their '***person***' factors, their personality features, autistic presentation, IQ, and how resilient they were when faced with CS. Participants also demonstrated that they all had differing abilities and the social skills that they needed to be able to cope, respond, and manage CS. Lastly, the '***time***' element of PPCT has been detailed throughout participant's narratives as core transitioning themes (CTT) and the '***context***'; element throughout the micro-, meso-, exo-, and macro- systems (mentioned previously).

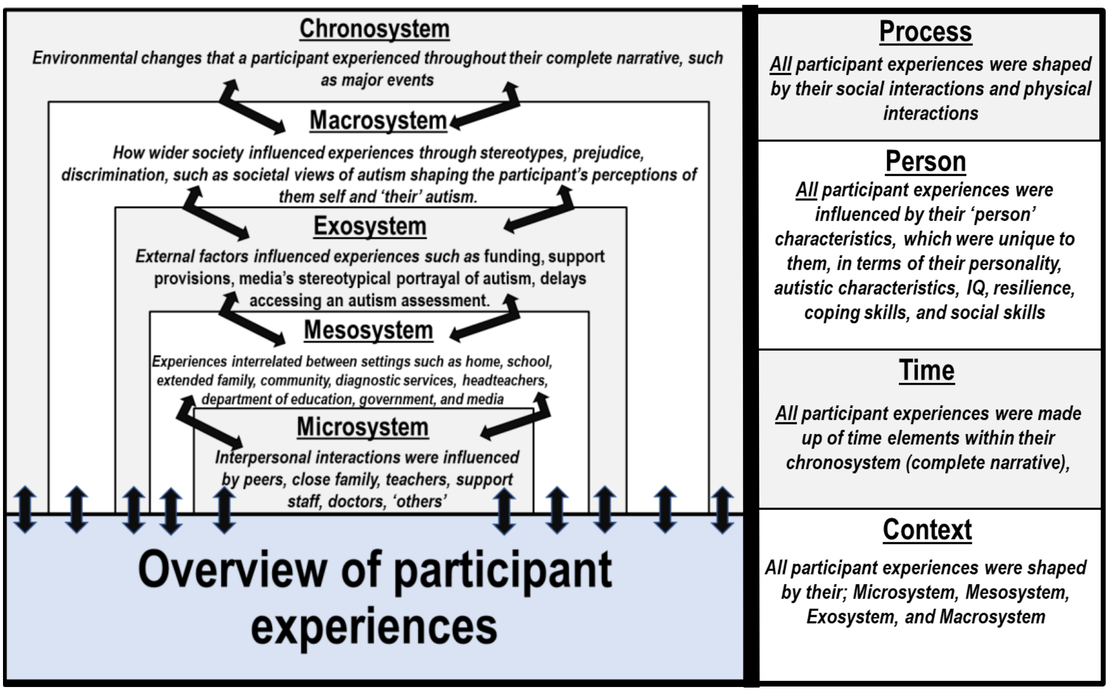


Figure 5.7: Bio-ecological and PPCT model of transitioning in relation to participants. Adapted from:[255, 256]

5.6.3 Theoretical change models

Participant results, particularly Jane's, demonstrated how difficult it was for them to adapt to changes, whether these were internal-horizontal (day-to-day) or external-vertical. The Ellaway (2017) theoretical model,[263] in Jane's results (chapter 4, section 4.6.12), illustrated how adapting to '***change***' was a complex process for her. It was evident that CSS greatly influenced her ability to '***recover***' from a change, although it did not happen immediately, and return to her original state, or as in her case, positively exceed her original state of '***performance***'.

MacGill (2011) theory[264] highlighted the importance of considering how key variables within participants' results influenced their abilities to adapt to change, particularly their typology. For example, in the context of Andy's results, I considered his lack of ability to adapt to his first secondary school experiences, noting (in reflective journals) any key variables that he lacked which made it difficult for him to adapt, such as '***potential***', '***connectedness***' and '***resilience***'. I also noted that he lacked emotional-social skills, which he needed to '***exploit***' any '***potential***' emotional-social opportunities in his secondary phase, reasoning that this was likely to be the reason that it was difficult for him to ‘***connect***’ with new peers, as well as not being ‘***resilient***’ enough to bounce back, adapt, to his new secondary emotional-social environment.

Prochaska et al (1992) theory[265] illustrated that the movement of change did not always occur in a linear manner, such as ‘***precontemplation***’, ‘***contemplation***’, ‘***determination***’, ‘***action***’, ‘***maintenance***’. For example, starting with ‘***action***’, all participants implied in their fabula transcriptions that they had a change in their intention to make friends when moving into the sixth form CTT. During this CTT, all participants described finding ‘their fit’, with likeminded individuals, which enabled them to ‘***maintain***’ positive emotional-social relationships, and this resulted in this CTT appearing as the most positive emotional-social experience for them all. In the context of the wider narratives, all participants, demonstrated that there were points in their narratives when they ‘***relapsed***’. This occurred for numerous reasons, such as ES-CS relating to ‘**being bullied**’, increasing Ac-CS pressures, and/or ‘**mental health**’ (MH) CS, and that this then had the direct consequence on them in terms of a notable deterioration in their state of health. When a ‘***relapse***’ occurred, participants’ results tended to demonstrate a point of ‘***pre-contemplation***’, such as in the case of Jane when she stated, “*girls would just constantly bitch …*”, and ‘**contemplation**’, that a change was necessary, such as in Jane’s decision to “*associate ... with boys*”(P203/00:32:59) instead.

Chapter 6: Discussion

6.1 Chapter overview

The previous chapters have provided analytical insight into the transitioning needs of five participants during their educational journeys. This chapter will discuss similarities shared by participants with the experiences shared by individuals (with autism) throughout relevant literature in this field. Commonalities of autism, unique differences and difficulties, stereotypes and typology will be considered. Whether findings met expectations and limitations, will be addressed.

6.2 Background

The robust narrative analysis of participant stories aimed to give insight into how the wider autistic population places meaning on their educational transitioning experiences, identifying that individuals have unique vertical and horizontal transitioning needs during their educational journey presenting as concurrent stressors (CS) that require concurrent stressor support (CSS). For apperception to be possible in this research, of CS and CSS needs, multitudinous variables were considered and their multifarious influence on each other. Categorising the educational journey into core transitioning themes (CTT) and transitioning subthemes (TST), I was able to divide and group influential variables into major '**academic**' (Ac) CS, major or minor '**emotional-social**' (ES) CS, which included CS related to this heading such as; bullying, discrimination, friendship, group interactions, mental health (e.g., anxiety, fears, phobias, self-harm, stress), social anxiety, stigma, and so on. I also considered any key childhood developmental features, that were likely to influence, change, and in some cases amplify CS and CSS needs. Fundamental influential factors were noted such as the relationship between others and the participant. I also considered how their autism potentially affected their expectations, perceptions and reactions, influenced CS, as well as self-concept, self-understanding, ego, typology, behavioural reactions such as self-harming and suicide attempts. In conjunction with this I acknowledged the influence of the media, the educational environment, educational policy and practice, on shaping the expectations, perceptions, and reactions of individuals and those around them. Through the systematic step by step approach taken in this research, adapted from the theoretical transitioning model of Schlossberg,[266-268] I was able to identify CS facing the participants during each CTT. In conjunction with this I have identified CSS provided, evidenced whether this was efficacious, and/or identified where CSS was needed.

6.3 Abbreviations and textual highlight coding

As in previous chapters, within the main body of the text, tables and figures: (1) Concurrent stressors (CS) are identified by being written in bold within single inverted commas. (2) Support received for the CS, otherwise known as concurrent stressor support (CSS), are identified by being written in italics and bold, within single inverted commas. (3) The term ‘participant’ specifically refers to those individuals with autism interviewed in the current study and participants who experienced CS are identified by being written in superscript within the relevant sentence. (4) By contrast, the term ‘individual’ will refer to individuals with autism whose results are reported in literature reviewed in chapter 1 and is, obviously, accompanied by relevant reference number(s). (5) The term general literature will be used to refer to research literature relating to individuals with autism outside of literature reviewed in chapter 1. (6) Core transitioning themes (CTT) will be used throughout to refer to education phases. (7) Any topics that appeared in research not in literature and/or appeared in literature not in research, will be written in bold and will be highlighted within a dashed-boxed area.

6.4 Findings

6.4.1 Emotional-social experiences

6.4.1.1 Friendship and social

‘**Emotional-social**’ (ES) CS was the primary major transitioning subtheme (TST) for all participants. Out of all participants CS throughout the research, the greatest frequency of major ES-CS (*f=9*) and minor ES-CS (*f=48*) occurred during the secondary CTT (as discussed in chapter 5, section 5.5). This ES transitioning subtheme (TST) was broken down into the most prevalent CS experienced by all participants during all CTT which were ‘**friendship**’ CS and ‘**social**’ CS. Both reflecting the core diagnostic characteristics of autism and mirroring findings in general literature.[10] Participants and individuals in general literature[7, 11-17] did not appear to innately learn social skills to be able to reduce these CS but rather needed to be taught them. General literature relating to the neurophysiological structure of an individual’s brain, differences in its physiological structure, the social part of the brain, its functionality and neurology, are proposed as the causal factors for ‘**friendship**’ CS and ‘**social**’ CS.[84, 336] These neurophysiological difference not only negatively impact on an individual’s ability to socially interact but also their ability to emotionally respond to stimuli,[85] as well as differences in their mirror neuron system (as discussed in chapter 1, section 1.6.1), ‘neurophysiology’.[89, 92-95] Mirror neuron system differences are also believed to negatively impact individuals’ social imagination, theory of mind (ToM),[96] and their ability to mirror and/or infer, others emotional states,[92, 93, 337] which was also evident for all participants.

Social imagination difficulties, the ability to interpret others’ mental states, to connect and empathise with them, was apparent for all participants, particularly during their earlier CTTs. Supporting general literature,[18, 20-22] all of the participants displayed lack of theory of mind (ToM) or ‘mind blindness’ at points in their narratives. These were times when they appeared to experience social perception difficulties, hindering their ability to form friendships with peers, resulting in ‘**friendship**’ CS and ‘**social interaction**’ CS. The general literature[97] reported that mirroring difficulties improved with age and this was evident for all participants in their latter CTTs when there was a reduction in their overall ‘**friendship**’ CS and ‘**social**’ CS.

‘**Friendship**’ was the second most frequent overall CS (*f=13*) experienced by all participants and ‘**social**’ was the third most frequent overall CS (*f=12*) experienced by all participants (as noted in appendices 5.1 - 5.5). The primary CTT reflected a time when participants, like the individuals in Makin et al,[217] had the least number of friends, and friendships were often non-reciprocal in nature. Secondary school appeared to be the most challenging CTT for all participants, when they all struggled to make friends and those who had friends usually had 2 or less. Alverson et al[191] noted similar difficulties for individuals during this schooling period with ‘**friendship’** and ‘**social**’ CS being at their most prevalent. According to the majority of parents in Peters et al[219] their children’s experiences mirrored the secondary experiences of all participants in their struggle to adapt to the external-vertical transition into secondary school, in particular with their ability to make new friends. For Jane, similar to individuals in Makin et al,[217] this transition appeared to result in a sense of loss, due to feeling sad leaving her best friend behind. A desire to make friends, be ‘like everyone else’ or ‘treated like everyone else’ was evident for all participants throughout their narratives and was in keeping with parents’ views in Cremin et al.[202] Similar to findings in Gelbar et al[208] and Lambe et al,[216] at various points in their narratives, all participants used social avoidance, as well as minimal contact with peers, as an attempt to manage their ‘**social**’ CS at school.

Adolescent transition points were viewed by all participants and individuals in Van Hees,[224] as a social opportunity in which they could find likeminded peers and/or would be able to adapt themselves, transform, into a different person that would fit in better with their adolescent social group. However participants and individuals in Cage et al,[198] expressed that they still felt isolated from their peers. Leigh shared that he was optimistic about going into the sixth form CTT, how once in sixth form his social interactions became easier, which he felt was due to his peers maturing, as well as finding likeminded peers with similar interests to him. Leigh’s experiences mirrored the findings from pre-university students in Van Hees et al[224] who expressed optimism about social interactions at university based on similar reasoning to those shared by Leigh. Jane mentioned how in sixth form she made friends with the “*weird* *kids*”,(P203/00:55:15) peers that she described as being like her. Karen used the same term as Jane to describe how she “*found… her place*” in sixth form with the other “*weirdos*”.(P202/0:22:34) It is important to note that neither Jane or Karen used these terms in a self-disparaging manner, they were said with smiles, positive tones and a sense of relief at finding likeminded peers.

Van Hees et al[224] findings revealed that individuals went through a social transformation during their move into sixth form and/or university, which was a commonality for participants.(Mark, Karen, Jane, Leigh) Statements were shared by participants relating to this topic. For example, Jane stated that she made a conscious attempt to socially transform in university, that she “*tried not to be too weird*”,(P203/01:04:43) so that she would be able to form friendships. Pre-university individuals in Lambe et al[216] shared a similar thought process to Jane, that due to worrying about making friends at university they consciously planned how they would socially interact prior to starting as an attempt to manage their worries before they arrived.

The university CTT appeared to be an overall positive social experience for all participants, except for an incident that Karen shared which occurred during her 2nd year and for Leigh that occurred in his final year. All participants at some point in their narrative, like the individuals in Gurbuz et al[209] and Van Hees et al,[223] described a reoccurrence of ‘**social**’ CS, especially when fitting in. They described social events like freshers events,(Jane, Andy)[209] and going out to pubs and clubs, when peers drank alcohol,(Mark, Jane, Andy)[223] as triggering a combination of feelings from being difficult, to exhausting and sensorily stressful. All participants shared that they received CSS when they joined an autism social group, where they felt they fitted in with their peers and in addition for Andy when he joined the Christian Union society. Joining social groups was something that individuals in Bolourian et al[196] also mentioned doing and benefitting from. Participants(Karen, Jane, Leigh, and Andy) expressed a reduction in ‘**friendship**’ CS during their university CTT, although, they said that they still had some negative social experiences, which was something that individuals in Gelbar et al[208] also shared. Although Andy expressed that he ‘fitted in’ in his Christian union group and the autism social group, he continued to struggle forming friendships at university and finding likeminded connections, which aligned with individuals in Sosnowy et al.[220]

In general, friendships for participants in university continued to be smaller and remained constant, when compared with their non-autistic peers.

‘**Loneliness**’ CS was specifically expressed by participants(Jane, Leigh, Andy) and individuals in Van Hees et al,[223] Gelbar et al,[208] and Makin et al.[217] Leigh described feeling lonely in his primary CTT however he went on to explain that in later CTTs, even though he spent a considerable amount of time alone, he became less lonely due to CSS he received from his books, that he considered to be his ‘best friends’. ‘**Loneliness**’ CS most frequently occurred for Jane during the university CTT and for Andy at various points during the university CTT. This is in keeping with more than half of the individuals in Gelbar et al,[208] who struggled socially, felt isolated and lonely during their university CTT and over 90% of individuals in Van Hees et al,[223] who also stated feeling overwhelmed and lonely during this time. All participants stated that their social needs were supported during their university CTT, which was the opposite of the experiences shared by individuals in Cai et al.[199]

6.4.1.2 Mental health

General

The general literature noted that at least 10% of individuals have one or more major MH condition(s).[123] Participants(Karen, Jane, Leigh, Andy) and individuals in Gurbuz et al,[209] Hastwell et al,[210] Anderson et al[193] and Humphrey et al[215] stated that MH-CS impacted their lives at various points in their educational journey. Out of all participants CS, the greatest frequency of ‘**mental health**’ (MH) CS (*f=15*) occurred during the university CTT (as discussed in chapter 5, section 5.5). Individuals in Hastwell et al[210] evidenced how ongoing exposure to CS often results in the appearance of secondary MH conditions, as was particularly evident when Jane was in secondary school (self-harming, suicide attempt) and Andy in university (depression).

Anxiety

All participants and individuals in Vincent[225] and Anderson et al,[192] expressed experiences of anxiety. The general literature also noted that anxiety was likely to be far greater for ‘higher functioning’ individuals when compared with lower functioning individuals, which was evident for all participants, particularly Leigh, who had a high propensity to worry[131, 132] and who had considerable fears, similar to individuals in Vincent,[225] Anderson et al,[192] and Bottema-Beutel et al.[197] Within the literature reviewed prevalence of individuals suffering with anxiety disorders ranged from 20%,[129] to 45%,[126] to 46%,[130] to 27%-47%.[128] However, in this research, although Jane received an official diagnosis, all participants were likely to have met the diagnostic criteria for ‘generalized anxiety disorder’ (GAD) at some point in their narrative.

External-vertical transitions from one educational phase to another appeared to trigger anxiety for all participants and individuals in Vincent.[225] Participants and individuals in Foulder-Hughes et al[207] found the move into secondary school particularly challenging. Individuals in Bolourian et al[196] shared their opinion that their MH deterioration in university was a direct consequence of negative secondary CTT experiences, highlighting the impact that this had on their future thoughts, resulting in suicidal ideations for some. As noted earlier, these findings were mirrored by the secondary CTT experiences shared by Jane, which highlighted how her negative experiences were followed by a deterioration in her MH, serious self-harming and a suicide attempt. Andy’s university CTT also reflected Bolourian et al[196] findings, that his negative secondary experiences resulted in the deterioration in his MH and an increase in his depressive symptoms. Internal-horizontal day-to-day transitions also triggered anxiety for all participants as well as individuals in Cai et al,[199] Foulder-Hughes et al,[207] Gelbar et al[208] and, according to parents, individuals in Peters et al,[219] particularly during the secondary CTT.

Depression

Prior to being diagnosed with depression during his university CTT, Andy did not share a diagnosis of any co-occurring condition. However, he did demonstrate signs of MH difficulties, a low mood, and excessive periods of sadness throughout his educational journey, findings that were supported by Cai et al[199] and Bolourian et al.[196] Andy’s findings mirrored that of individuals in general literature,[138] appearing to be at a greater risk of developing depression due to being diagnosed later in life, during the university CTT. Andy received CSS for his depression, especially benefitting from ‘***counselling***’ and ‘***autism specific***’ CSS, which appeared to alleviate his symptoms, as mirrored in general literature.[139] Throughout this research, at varying points in their narratives, all participants displayed some depressive symptoms such as; low mood, low self-esteem, lack of confidence, pessimistic views of their future, suicidal behaviours, sleep issues, eating disorders[24] (general literature), concurring Van Hees et al[223] stated that at least two-thirds of individuals have depressive symptoms.

Self-harming and suicidal ideation

The suicidal ideation and self-harming episodes experienced by Jane are not uncommon in those with autism. The general literature,[138, 155-157] demonstrates that suicide risk and self-harming risk were significantly greater for individuals when compared with their non-autistic peers,[155-157] particularly suicidal ideation,[196] even more so when they had co-occurring MH conditions and exacerbated further the longer it took for them to be diagnosed with autism.[138, 157] Licence et al, general literature,[338] evidenced that 24.1% of individuals self-harmed, and this risk increased dramatically when they had co-occurring ADHD characteristics, in particular impulsivity and hyperactivity, which was the case for Jane. Although it is important to note that according to Hunsche et al[339] (general literature), the prevalence of individuals who are self-harmers who go on to have suicidal ideation is low, at approximately 4 - 9.6%. The general literature[158, 159, 161] and Jane evidenced a link between self-harming episodes and a variety of CS triggers not just MH-CS, such as '**social**' CS and '**loneliness**' CS,[161] that one cannot simply state MH-CS is the cause.[158, 159] All participants masked their autism differences and experienced CS, they lacked a sense of belonging at times. In relation to Jane it is likely to concur that she was at a greater risk of suicide because of these reasons[340] (general literature).

ADHD

Jane mirrored the commonality of individuals in Bolourian et al[196] having co-occurring ADHD and MH conditions, which appeared to be more likely when individuals[166] (general literature) had 'higher functioning' autism. Although Mark was not diagnosed with ADHD he did demonstrate characteristics, such as talking excessively with a hyperactive presentation, which concurs with those given in the general literature.[341]

Eating disorders

Eating disorders (ED), in the form of food selectivity are relatively common for individuals according to general literature,[140, 141] ranging from 46 to 89%.[136] In Nickel et al[342] (general literature) anorexia was found to co-occur for 4.7% of individuals, and the risk increased further to 18% when the individual had co-occurring ADHD, which was also the case for Jane. Jane and general literature[143, 144] demonstrated a relationship between autistic characteristics going unnoticed, undiagnosed and unsupported, potentially triggering co-occurring ED, particularly anorexia. With Barrionuevo et al[142] (general literature) emphasising the importance of children presenting with ED being considered for an autism referral.

OCD and phobias

Leigh expressed that he had undiagnosed OCD, known to be prevalent for individuals in Cai et al[199] and Bolourian et al.[196] His results are supported by that seen in general literature[133, 134] which evidences individuals OCD symptomology (anxiety triggers) as stemming from fears, phobias,[133, 134] animal worries, environmental concerns,[134] which were all present for him. Leyfer et al[123] (general literature) noted that 44% of individuals in their study had specific phobia disorders, something that all participants were likely to have in relation to their social presentation meeting the criteria for social phobia. It is important to note that Andy's presentation of 'school phobia', and all participants presentation of 'social phobia', as discussed in general literature,[135, 343] could have been an early indicator of their undiagnosed autism requiring referral for an autism assessment.

6.4.1.3 Bullying and discrimination

'**Being bullied**' CS was experienced by the majority of participants, who mentioned that they were bullied at various points in their narrative, during the primary CTT$^{\text{(Jane, Leigh)}}$ and during the secondary CTT.$^{\text{(Mark, Jane, Leigh, Andy)}}$ but there was no specific mention of this CS during either sixth form or university CTT by participants. This contrasts with the findings in Gelbar et al,[208] where 25% of individuals experienced indirect bullying, teasing or discrimination, by peers at university. However, amongst the participants, there were two major social incidents at university for Karen and Leigh, namely being kicked out by flatmates$^{(Karen)}$ and being forced to pay all the bills,$^{(Leigh)}$ that are potential examples of indirect bullying.

In general, '**being bullied**' appeared to be common for participants$^{(Mark, Jane, Leigh, Andy)}$ and the majority of individuals in the literature reviewed.[192, 193, 197, 204, 208, 211, 215-217, 224, 226] Reasons as to why bullying took place were not specifically explained by participants, however, they suggested that it may have been because they were '*weird*',$^{(Karen, Jane)}$ socially different to their peers. This idea is supported by views of Makin et al[217] who proposed that individuals were bullied due to their '**social**' differences. All participants, plus individuals in Makin et al[217] and Humphrey et al,[215] appeared to be exploited and/or victimised by their peers at some point during their narrative due to their ES-CS and/or vulnerability. Leigh's experiences of being forced to pay all the utility bills, highlighted his vulnerability, how he was taken advantage of by his peers, concurring with the stories of individuals in Makin et al.[217]

Unstructured social times, such as breaktimes, appeared to be particularly challenging for some participants,$^{(Jane, Andy)}$ and individuals in Makin et al,[217] Lambe et al,[216] Humphrey et al[215] and Peters et al.[219] Individuals sought a safe place to go during break times where they could avoid '**being bullied**',[216, 217] and/or have staff around as a means of protection.[215] Alongside this, the ineffective transition support experiences shared by Jane, who was given access to the special educational needs (SEN) unit then refused entry a few weeks later due to lack of autism diagnosis, supports Peters et al[219] claim that ineffective support was likely to result in bullying. Evidenced throughout by all participants, individuals in the general literature[10] and literature reviewed,[217] was that individuals lacked social skills,[10] which was likely to be a major factor in CS '**being bullied**', as well as '**loneliness**' and '**social isolation**'.[217]

6.4.1.4 Groups interaction

'**Group**' CS, interacting with peers in a group dynamic, whether academically or socially, was a CS for the some participants$^{(Mark, Karen, Andy)}$ and individuals in literature reviewed.[192, 193, 195, 199, 205, 219, 226] The CTT when '**group**' CS most frequently occurred for participants$^{(Mark, Andy)}$ was during primary school, when they found the social aspects of group activities stressful. Individuals in Dixon et al[206] shared similar feelings about the social aspects of groups being too stressful for them during the primary CTT, noting how they were not able to engage in transitioning CSS prior to starting the secondary CTT due to its group dynamics. The majority of parents in Peters et al[219] also felt that their autistic child avoided group interactions, that breaktimes were spent doing activities on their own. This was similar to the experiences shared by Leigh.

During the university CTT '**group**' CS experiences,(Karen, Andy) mirrored the findings of Van Hees et al,[224] with academic group work during this CTT often being unavoidable. Specific '**group**' CS shared by participants,(Karen, Andy) individuals in Van Hees et al,[224] were tasks such as academic group work as a requirement of their degrees, as well as difficulties experienced during organised university social group activities. It is important to stress that group interactions did not always result in CS for participants,(Mark, Karen, Jane, Leigh, Andy) in keeping with the experiences of individuals in Bolourian et al.[196] During the university CTT, Andy shared positive group interactions through Christian union, Jane through Scouts, Guides and Track (athletics), and all participants through an autism social group (where they appeared to meet likeminded peers).

Appearing in research not in literature

There were a number of aspects revealed in the narratives that did not appear in the general literature or literature reviewed.

(1) **Trichotillomania:**(Jane) This condition is not reported as commonly co-occurring with autism, however, it is believed to commonly co-occurring with anxiety disorders,[344, 345] which Jane had.

(2) **Higher rates of bullying at secondary school than rates in literature reviewed:**(Mark, Jane, Leigh, Andy) This research evidenced that 80% of participants experienced '**being bullied**'(Mark, Jane, Leigh, Andy) CS during their secondary CTT. This was not in keeping with the rates suggested by Peters et al[219] whose study concluded that 53% of individuals were bullied during their secondary CTT.

However it must be noted that Peters et al[219] data was based on parental perspectives of their child’s experiences and was not first-hand perspectives from the individual, which might suggest that a greater number of individuals were being bullied which their parents were unaware of.

(3) **Social exhaustion**:(Jane) Jane said that she struggled with this condition which appeared to result from over-socialising during the sixth form CTT.

(4) **Shyness and timidity**:(Andy) Appearing to impact Andy’s social abilities.

(5) **Abuse from peer’s parent:**(Jane) Jane suffered abuse due to her challenging behaviours.

(6) **Being labelled as a problem child:**(Jane) Jane appeared to be labelled due to her challenging behaviours.

Appearing in literature not in research

There were a number of aspects that appeared in the general literature or literature reviewed that were not revealed in the narratives.

(1) **Food selectivity:** Although commonly reported in the general literature as co-occurring with autism,[136, 140, 141] none of the participants talked about food selectivity within their narratives.

(2) **Post-Traumatic Stress Disorder (PTSD):** PTSD has been shown to co-occur in individuals by Cage et al.[198] The general literature proposes that individuals are 32% more vulnerable to PTSD[178] due to increased exposure to stress and trauma as well as features of cognitive inflexibility and obsessive thought patterns.[176, 177] Participants did not mention PTSD however, from the presenting features of Jane it is likely that she may have met the criteria for a diagnosis of PTSD.[52]

(3) **Psycho-social age**: In general literature, ‘**social**’ CS often was related to individuals psycho-social age, which appeared to differ from developmental expectations based on their chronological age and a reason for ‘**social**’ CS with their peers.[113-116] Such developmental milestones were not discussed by participants of the current study.

(4) ‘**Self**’: Individuals presented with self-concept and self-understanding differences and difficulties in general literature.[117-120] In the context of this research, participants’ experiences shared were not sufficient enough to compare findings with literature.

However, participants' 'self-belief' differences and CS evidenced that they did face Ac and ES barriers. Firstly, understanding their potential, and secondly in achieving their academic,[121] as well as emotional-social potential.

(5) **Structured social opportunities**: Although academic peers were mentioned as a source of friendship, by individuals in Lambe et al,[216] this was not referred to by participants, in fact Karen stated the opposite, that she experienced '**group**' CS due to finding it difficult to interact with peers on her course in a structured context.

(6) '**Social**' **CS worsening with age**: Participants' experiences did not correlate with the findings in Mazefsky et al,[30] (general literature) they did not demonstrate that their '**social**' CS worsened with age and that this resulted in greater '**loneliness**' CS. In fact, the opposite seemed to be true for the majority of participants,(Jane, Leigh, Andy) as they appeared to be less lonely during the university CTT when compared with earlier CTT.

6.4.2 Academic experiences

'**Academic**' (Ac) CS was the second major transitioning subtheme (TST), a common educational finding, as expressed by individuals in Makin et al.[217] All participants faced Ac-CS during their narrative, supporting the findings in the literature reviewed.[199, 200, 213, 216, 217] Out of all participant CS throughout this research, the greatest frequency of major Ac-CS (impacting state of health) (*f=15*) occurred during the university (BSc.) CTT (as discussed in chapter 5, section 5.5).

'**Time**' CS, a Ac-CS, was the fourth most frequent CS (*n =10*) experienced by all participants at points in their narratives (as noted in appendices 5.1 - 5.5). '**Time**' CS presented in many forms such as running out of time in exams, when doing work set, difficulties effectively managing time, and these appeared to fundamentally challenge all participants and individuals in literature reviewed.[196, 199, 200, 208, 216, 220] Many participants(Leigh, Andy) and individuals in Sosnowy et al,[220] struggled with '**time**' CS during their sixth form CTT when they didn't get the extra time they needed for exams. To level the academic playing field and reduce '**time**' CS, it was clear in this research, from individuals in Camarena et al[200] and Cai et al,[199] that individuals needed to be supported by having reasonable adjustments in place, such as extra time in tests, extra time in exams and extensions to deadlines. Following their autism diagnosis and disclosure to their educational establishment, all participants in the current research were offered similar time adjustments for their studies. However, it is also important to note that sometimes participants,(Mark, Leigh, Andy) individuals in Bolourian et al[196] and Cremin et al[202] did not accept CSS provided, presumably due to not wanting to be different to their peers. Finally, it is vital to consider Leigh's narrative which highlighted that the 25% extra time provision (UK standard reasonable adjustment) was insufficient for him, that he still ran out of time, demonstrating that standard provisions for some may be insufficient.

Other major Ac-CS ranged from subject specific content or processing difficulties with English and maths, to the general academic challenges experienced as a result of motor skill difficulties and an insistence with sameness that are often associated with autism. For example, '**English language**' CS, particularly when dealing with abstract concepts, appeared to challenge participants during the primary(Mark, Jane, Leigh) CTT, secondary(Mark, Jane) CTT and individuals in Tobias.[222] '**Math'** CS, were described by participants during the primary(Mark, Leigh) CTT, secondary(Andy) CTT, throughout all CTT,(Leigh) as well as by individual in Anderson et al.[193] These findings were also reflected in Wiorkowski[226] who stated that individuals experienced English, math and science challenges, resulting in them lacking the necessary foundations in these subjects. '**Fine motor skill**' CS was experienced by participants during their primary(Mark, Jane, Leigh) CTT and secondary(Mark) CTT, and mentioned by individuals in Cai et al.[199] These CS appeared to impact handwriting abilities, legibility, as well as speed and thus required additional time in class and exams. Leigh also mentioned struggling in the primary CTT following instructions due to a '**rigid need to complete work in a certain manner**' CS, resulting from insistence for sameness, which reflected findings in general literature.[7, 24] Finally, participants(Leigh, Andy) and individuals in Dillon et al[205] mentioned Ac-CS during their secondary CTT because of peers who were too noisy and didn't want to learn, and teachers were unable to effectively manage this teaching environment.

It was evident that some participants' '***teachers***' provided Ac-CSS by adapting their teaching style to meet unique learning needs, during the secondary(Jane, Leigh) CTT and sixth form(Jane) CTT. The remaining three participants did not specifically mention that teachers had adapted their teaching style which may suggest that Peters et al[219] estimate of less than half of teachers specifically adapted their teaching style for individuals is likely. However, please note that this research does not evidence that participants were not provided with Ac-CSS through teaching adaption at some point during their narratives, this may have occurred but was not shared and/or may have occurred without them being aware of it. It is clear throughout all narratives that participants received some form of Ac-CSS from '***teachers***', '***support staff***', particularly during their sixth form and university CTT, often, but not always, following their autism diagnosis.

In keeping with Lambe et al,[216] participants(Karen, Leigh) shared their academic excitement about going to university, at being able to specialise in their favourite subjects as well as being taught by experts in their field. Overall participants, at the point of the research interview, had academic success, either by receiving good grades for their university year or by successfully completing their degree or masters. However, in keeping with Gelbar et al,[208] all participants' academic success appeared to go hand in hand with ongoing Ac-CS, which increased during the university CTT. The wide variety of Ac-CS were experienced in university by participants and individuals are summarised as following. Jane and individuals in Cage et al[198] and Gurbuz et al,[209] had problems with feedback which they saw as being abstract or unclear. Difficulties with academic deadlines, timed assessments, note taking and suffering from academic overload, was experienced by all participants and individuals in Bolourian et al.[196] Answering questions in class was difficult for Andy and individuals in Anderson et al.[192] The lack of clear instructions challenged Karen and individuals in Peters et al.[209] Managing their unstructured time was problematic for Andy and individuals in Cage et al.[198] Sensory distractions challenged Jane, Andy and individuals in Wiorkowski.[226] In conjunction increasing demands, and Ac-CS, at university, Andy mentioned as correlating with an increase in his ES-CS, particularly with his depressive symptoms. Separating Ac-CS from ES-CS at university proved difficult for both participants and individuals in Van Hees et al,[224] particularly '**group**' CS and the '**social**' CS aspects of university.

The findings from this research, the general literature[66, 99] and individuals in Lambe et al,[216] corroborate the view that neuro-diverse individuals, including those with autism, have executive functioning (EF) difficulties which result in forms of EF-CS that impacts them negatively and to varying degrees, academically, emotionally and socially.[66, 99, 216] For example, Mark and individuals in Cai et al[199] talked about difficulties with organisation. Karen and individuals in general literature[86, 109] had struggles with processing information and with their working memory. Jane and individuals in Cai et al[199] became distracted easily. Jane and individuals in Hastwell et al[210] sometimes struggled with the way teachers delivered their material in lessons. Problem-solving appeared to be difficult for Andy and individuals in Hastwell et al.[211] Whilst time management was a challenge for Mark and individuals in Van Hees et al.[223] In the educational context, working memory difficulties were evident for all participants and was also noted in general literature,[86] particularly in relation to their ability to store and use information in an efficient manner, resulting in '**time**' CS and a need for '***additional time***' related Ac-CSS.

Individuals in Dixon et al[206] suggested that EF-CS increased with age, which correlated with all participants who experienced greater EF-CS during the university CTT. Individuals in Hillier et al[213] proposed that EF-CS was likely to be due to increasing academic independence demands, CSS demands increasing, and that this appeared to have nothing to do with individuals academic abilities. In the case of Andy, individuals in Lambe et al,[216] increased Ac-CS and ES-CS impacted their ability to do academic work, their state of health and vice versa. During the university CTT all participants EF-CS mirrored those of individuals in Bolourian et al,[196] taking the form of difficulties organising their time effectively, getting work in on time, completing timed assessments and keeping up with note taking in lectures. In addition, Karen shared '**processing**' CS due to difficulties processing what lecturers were saying and then being able to note this down in the time given, as also was reflected in general literature.[86, 109]

Due to the fact that EF-CS varied amongst all participants and individuals in general literature,[101] in order to be effective, the CSS provided needed to be person centred (identifying and supporting their specific EF-CS). In addition, Ac-CSS needed to be provided throughout their childhood and into their adulthood.[100] As pointed out by parents in Camarena et al[200] it was crucial that '***autism specific***' CSS was in place as soon as the individual started their university CTT to avoid academic obstacles. This was not possible for Karen and Andy due to '**being undiagnosed ASC**', which resulted in them not being able to access '***autism service***' CSS, '***disabled student allowance***' (DSA) CSS when they started their university undergraduate courses. Their narratives demonstrated that Ac-CS and ES-CS were greater prior to accessing '***autism specific***' CSS reflecting the points raised by parents in Camarena et al.[200] It is unclear in this research whether participants^(Mark, Jane, Leigh) EF-CS related to lack of specific EF CSS or not, as they shared that they had CSS, during their university (BSc) CTT, but still were having increasing EF-CS.

Appearing in research not in literature

There were a number of aspects revealed in the narratives that did not appear in the general literature or literature reviewed.

(1) **The academic jump from GCSE to A-levels:**^(Leigh, Andy) Leigh and Andy both mentioned experiencing Ac-CS transitioning from GCSE exams in the secondary CTT to A-Level exams in the sixth form CTT. Leigh had to transfer from A-level to BTEC, which covered a broader range of topics, due to the difficulties he experienced.

(2) **The academic pressure to get high grades:**^(Karen) Karen shared that she felt pressurised during her secondary CTT to get 'A grades', that the school had instilled the belief in her that without an 'A grade' in an exam she would not be successful in life, something she later realised was not the case.

(3) **Exam techniques and difficulty moving on to a new question:**^(Andy) Andy found exam techniques particularly challenging, especially the ability to move on to the next question during an exam paper when he was not able to complete a question.

(4) **Fear of failing academically:**^(Mark, Karen, Andy) Three participants stated that they feared they would fail academically, namely Andy during the secondary CTT, Mark during university CTT and Karen during university (MSc) CTT.

(5) **Teachers prioritising core subjects to the detriment of favourite subjects:**^(Jane) Jane expressed concern during her secondary CTT due to teachers making her prioritise core subjects, such as English, to the detriment of her favourite subjects, history, and geography.

Appearing in literature not in research

There were a number of aspects that appeared in the general literature or literature reviewed that were not revealed in the narratives.

(1) **Secondary schools providing more structured environment:** Parents in Dillon et al[204] described secondary school as being more fitting for individuals due to being more structured, however this was not an experience that was shared by any of the participants.

(2) **Gastrointestinal co-occurring ailments:** Physical ailments relating to the gastrointestinal system are believed to co-occur with EF difficulties,[62] this was not mentioned by participants.

(3) **Factors preventing individuals from reaching full-potential and resulting in them dropping out of university:** EF difficulties negatively impacting individuals' ability to reach their full academic potential,[103] and being a major reason for them dropping out of university,[104] was not addressed by participants. However, as the nature of this research involved participants who were either still attending university or had successfully completed university, it was not possible for the researcher to reflect on those who dropped out of university.

6.4.3 Autism, self and others

All participants in this research expressed that they felt different to their peers. The dominant CTT when all participants were aware of their autistic characteristics was during their secondary CTT, with Jane and Leigh mentioning that they knew they were different as early as their primary CTT. The secondary CTT appeared to be a time when all participants, and some individuals in Bottema-Beutel et al[197] and Dillon et al[204] were least understood and supported by teachers,[204] often negatively labelled, and left out by peers, all of which appeared to impact them greatly academically and emotionally-socially.[197] Karen and Jane, referring to themselves as 'weird', 'not normal', 'a freak', 'having a bad brain', similar to individuals in Makin et al,[217] and that they needed to act normal, mask their autism to fit in with their peers.[193, 217] All participants shared experiences of others behaving negatively to their autism, which was something individuals in Humphrey et al[215] believed shaped this self-perception.

Participants(Mark, Jane, Andy) demonstrated the influence that the ***macrosystem*** had on them,[255, 256] how they experienced direct stigma and stereotypical views from others associated with being autistic, mirroring individuals' experiences shared in literature reviewed.[192, 196, 209, 210] Mark stated that he became aware of autistic stereotypes during his secondary CTT, when he began to realize he was 'autistic' but wasn't yet diagnosed. He expressed concern about the stereotypical portrayal of autistic people, that he was nothing like this, and that he worried about his peers reaction to him telling them that he was autistic. This was also reflected on by Andy who shared that he became very concerned following his autism diagnosis, during the university CTT, as he felt that 'autistic' was a term "*used to insult people*".(P205/00:04:58)

The majority of participants(Mark, Karen, Jane, Leigh) demonstrated an awareness about how autistic characteristics related to them, however this appeared to vary greatly and was something that Alverson et al[191] also concurred in their research. The ability of all participants, and individuals in Beardon et al,[195] to understand their autism, as well as understand their peers better, appeared to improve with age. Participants and individuals in Cremin et al[205] also expressed an improvement in their overall state of health when they understood their autism and when they were supported well within their educational phase.

Literature emphasises that it is crucial that staff recognised an individual's challenging behaviour triggers rather than labelling them as a 'problem child', which happened to Jane, and was highlighted by individuals in Makin et al[217] and Tobias et al.[222] Day-to-day transition stressors appeared to be a major causal factor in triggering challenging behaviours for Jane and individuals in Dixon et al.[206] Some parents in Cremin et al[202] suggested that puberty amplified their child's challenging behaviours, which participants(Mark, Leigh) also commented on. Leigh noted how during puberty he experienced his greatest '**social**' CS interacting with his peers, and how this improved post-puberty.

Jane openly shared how she presented with challenging behaviours, particularly during her secondary CTT, living up to the label she had been given by others as a "*problem child*",(P203/00:16:42) and that she felt this resulted in teachers behaving negatively toward her, which then exacerbated her behaviour. Throughout Jane's secondary and sixth form CTT, meltdowns, and sometimes violent outbursts, were also common for her. Sixth form staff appeared to take a positive empathetic response approach to Jane's challenging behaviours and provided her with '***the cupboard***' as a safe space to go when overwhelmed. This CSS proved successful and contributed towards an improvement in her overall state of health. Having a safe space to go in times of distress, like '***the cupboard***', was something individuals in Cai et al[199] promoted. Sixth form staff appeared to offer Jane a whole school understanding of autism, adapting to meet her unique needs, supporting her Ac-CS, ES-CS and day-to-day triggers, which was similar to the experiences shared by parents in Dillon et al.[204]

Finally, individuals in Sosnowy[220] noted the importance of providing individuals with a platform to influence the social arena, which occurred for Jane when she was appointed as an autism ambassador. Wiokowski[226] emphasised the importance of enabling individuals to positively influence the lives of others with autism, and encouraging their personal growth, which also occurred for Jane through this ambassador role.

6.4.3.1 Disclosing autism and asking for support

It appeared that the ***exosystem***,[255, 256] particularly diagnostic services, others, stigma, and autistic stereotypes, played a significant part in participants(Mark, Jane, Andy) and individuals lives.[192, 196, 209, 210] Not wanting to draw attention to oneself, masking their natural behaviours or characteristics, and, wanting to be considered as being normal, were points raised by several participants(Mark, Andy) as well as individuals in Camarena et al[200] and Humphrey et al.[215] Hesitancy about autism appeared to prevented individuals from disclosing their autism. Dixon et al[206] highlighted that support was the only reason some individuals disclosed, possibly mirroring Jane's mum's, and Andy's mum's, reasoning for delaying their child's autism assessments, because they both had the support they needed without a formal diagnosis. However, when Jane arrived at secondary school, and Andy at university, it was clear an autism assessment, diagnosis, was needed to get the '***specialist autism***' CSS they needed.

Once diagnosed, participants(Mark, Karen, Jane, Andy) expressed '**disclosing autism**' CS and were unsure whether to disclose their condition to their educational provider and/or peers. Participants,(Karen, Andy) and individuals in Bolourian et al,[196] shared their apprehension disclosing autism. They appeared to have the belief that disclosing their autism would mean they would be treated differently by lecturers, talked down to, treated as if they weren't intelligent enough, and also that peers would interact with them differently. Disclosing to professionals for the purpose of CSS seemed to be acceptable for participants and individuals in Gelbar et al,[208] however, many still chose not to disclose to their peers. Mark's struggle with '**disclosing autism**' CS continued during the sixth form CTT and this delay resulted in him not being able to have reasonable adjustments in place in time for his A-level exams. Throughout participants narratives, it appeared that parental involvement was a crucial component in ensuring that their child's autism support needs were met through disclosure. Individuals in Mitchell et al[218] evidenced that parents played a significant role in supporting their child regardless of age or educational stage.

Whether diagnosed with autism or not, all participants were provided with some form of CSS throughout their educational provider due to their presenting needs. Some participants,(Leigh, Andy) individuals in literature,[196, 198, 202] often refused to accept the support offered because they did not want to stand out or be treated differently from their peers, according to parents in Cremin et al,[202] or because they felt they didn't warrant it or that they didn't want special treatment, as noted by individuals in Bolourian et al[196] and Cage et al.[198] During the university (BSc and MSc) CTT Leigh refused to accept additional support available to him through disabled student allowance (DSA) because he felt he was not disabled enough to warrant this and did not want to have special treatment. Leigh, individuals in Bolourian et al[196] and Cage et al,[198] also mentioned not wanting to 'make trouble' and ask for help or say they were struggling. Participants' views were reflective of Van Hees et al[223] whereby the majority of their university individuals expressed doubts as to whether they would disclose their autism, only disclosing when they specifically needed support. However such delays in accessing support, due to late diagnosis, heightened anxiety for Andy and this was also seen in individuals in Anderson et al.[193]

6.4.3.2 Co-occurring conditions

As mentioned earlier in relation to mental health (section 6.4.1.2), co-occurring conditions, including other neuro-diverse conditions and mental health (MH) conditions, were common for the majority of participants,(Jane, Leigh, Andy) individuals in general literature,[7, 346] individuals in Lambe et al[216] and Bolourian et al.[196] Participants(Karen, Jane, Leigh, Andy) had at least one co-occurring condition in addition to their autism, which was likely to exacerbate their CS. Although Mark displayed ADHD characteristics, he did not share any co-occurring conditions and/or present symptoms which might reflect CS resulting from this. Jane’s results supported findings in general literature,[7] that a proportion of individuals will also have ADHD, which necessitates a dual diagnosis of both autism and ADHD, which prior to 2013 was not possible. Karen shared her belief that she had undiagnosed dyspraxia (developmental co-ordination disorder (DCD)), something that was suggested by her teachers and her parents as a possible reason for her CS during her primary CTT and secondary CTT. General literature,[168, 347] and individuals in Lambe et al,[216] evidenced how dyspraxia (DCD) often overlapped with autism. Miller et al[168] (general literature) stated that 95% of their individuals (with autism) also had DCD. Karen shared her belief that her difficulties with physical education (PE) and getting a low grade in this subject was a direct consequence of having dyspraxia (DCD), although this could have been related to motor skill difficulties associated with autism[7, 24] (general literature) and/or the similarities in behavioural aspects of both conditions[167] (general literature).

General literature[347] indicated that dyslexia can also overlap with autism, which was the case for Jane. Hofvander et al[169] stated that dyslexia co-occurred for approximately 14% of their individuals. Dyscalculia was also considered an overlapping condition[7, 347] with approximately 3-5% of individuals in general literature[170] having both conditions. Dyscalculia was not shared by any participants, however ongoing ‘**math**’ CS, was shared by Mark and Leigh, and was noted by individuals in Anderson et al,[193] which might possibly indicate dyscalculia was a factor requiring further investigation.

It is common for individuals in general literature[7, 23, 28-30, 346] to have restricted repetitive behaviours (RRB) and obsessive interests,[7, 23, 346] with RRB reducing with age, and obsessive interests tending to remain throughout their lives.[28-30] This was evident for some participants, with Jane's and Leigh's obsessive interests in history and wildlife conservation respectively. Although this did not appear in the literature reviewed, echolalia (repeating phrases and words) was also a common behavioural characteristic of individuals in general literature.[7, 23, 30] Echolalia was something that Leigh, and his family, were proud to share, particularly his amazing abilities to mimic famous quotes, voices, and singers. Interestingly Leigh's echolalia, was referred to by him as being a comfort mechanism, especially when he was alone or feeling lonely. There was no mention of co-occurring sensory processing disorder (SPD) by any participants. However Andy and Jane both shared '**sensory**' CS, which is likely to be indicative of this condition, and was very closely linked with individuals' experiences in general literature.[7, 24]

Sleep disorders, which might present as '**difficulties maintaining a regular sleep cycle**' CS was evident for Mark during the university CTT. Sleep disorders are believed to be common for individuals in general literature, as evidenced in Diaz et al[148] systematic review which estimated that this occurred for approximately 50-71%. However, the commonality of '**sleep**' CS was not shared by the other participants, and does not support Diaz et al[148] (general literature) claim that 50% plus have '**sleep**' CS. However, it is important to note that it is quite likely that participants may have had '**sleep**' CS but did not feel it was relevant to mention their sleeping habits within the context of their narratives, and thus the research findings may not reflect the true picture.

Appearing in research not in literature

There were a number of aspects revealed in the narratives that did not appear in the general literature or literature reviewed.

(1) **The educational transitioning experiences of undiagnosed individuals:**(Mark, Karen, Jane, Leigh, Andy) Experience prior to autism diagnosis, was not addressed in literature and, thus, this research has gone further to fill this gap in knowledge. '**Being undiagnosed**' (with autism) was the most frequent CS (*n =15*) experienced by participants in this research (as noted in chapter 5) and had a major impact, or was a major ES-CS, on participants' transitioning experiences. Background literature such as the latest BMA 2019 report, claims that the current assessment process is "*failing a generation*".[78(p1)]

This research supports the claim that there is a lengthy assessment process in the UK, a process which starts with an initial school identification, followed by referral, then several assessment appointments, before they receive an autism diagnosis. Currently data, from general literature, suggests that it takes an average of at least 3.6 years in the UK for an autistic child to be diagnosed with a condition that they were born with, and this time is likely to be longer for 'higher functioning' individuals (in general literature),[78-80, 348, 349] as was the case for participants. Based on literature findings and participant data, it is evident that '**being undiagnosed**' (with autism) CS is common in the earlier CTT or educational phases. Findings from this research indicated that no participant was referred to be assessed for autism during their primary CTT, likely to be due to their subtle presentations. It also showed that it was rare amongst participants to be diagnosed prior to sixth form, and that this late diagnosis often resulted in lack of necessary Ac-CSS and ES-CSS in time for exams.(Mark, Karen, Jane, Andy) and this is likely to have impacted on their overall health, well-being, and academic performance.

(2) **Parental experiences of seeking a diagnosis for their child with autism:** During the primary CTT, parents(Karen, Jane, Leigh, Andy) appeared to be discouraged from pursuing an autism assessment by support staff and medical professionals. Jane and Leigh's parents were both led to believe during the primary CTT that an autism diagnosis would be detrimental and negative, for their child.

Appearing in literature not in research

There were a number of aspects that appeared in the general literature or literature reviewed that were not revealed in the narratives.

(1) **Restricted repetitive behaviours (RRB):** RRBs are believed to be common for individuals, as discussed in general literature.[26, 27, 279, 280] RRBs were not explicitely referred to by participants or in the literature reviewed. However, one cannot infer from this that RRB did not occur amongst participants, it may simply be evidence that they were not part of the narrative being told, and/or, these experiences were lost possibly due to episodic memory difficulties.

(2) **PICA**: The eating of non-edible objects, believed to occur for approximately 25% of individuals, was mentioned in general literature[31, 32] but not referred to by participants or in the literature reviewed. Bortz[33] (general literature), suggested that individuals with a greater level of intellectual disability were more likely to have PICA, which might be the reason why participants in the current research, who did not have an intellectual disability, did not share experiences of this condition. Hergüner et al[34] (general literature) indicated that PICA was more prevalent when an individual also has OCD characteristics, however Leigh, who had OCD characteristics, did not share experiences of PICA. Lichtblau et al[36] (general literature) shared that PICA sometimes took the form of trichophagia, eating hair, which is closely linked to trichotillomania, which Jane suffered from. However, although she mentioned pulling out her hair, she did not say that she ate it. Finally, it is important to stress that, as pointed out in Slocum et al,[35] (general literature) it was common for individuals to hide having PICA, which infers that some participants may have chosen to hide current and/or previous PICA from me (the researcher).

(3) **Less commonly occurring conditions**, **such as epilepsy and psychosis:** Due to the nature of this research, and the limited number of participants, it is understandable that some points raised in related literature would not appear in this research. Particularly some less frequent co-occurring conditions referred to in general literature such as epilepsy which is believed to co-occur for 9% of individuals,[172, 173] and psychosis.[174, 175]

6.4.4 Transitioning between educational phases experiences

The external-vertical transition between educational phases or core transitioning themes (CTT), appeared to be an ‘**emotional-social transitioning**’ (EST) CS or a major anxiety trigger, for all participants, reflecting individuals’ experiences in Vincent.[225] Parents in Makin et al[217] demonstrated how unhappy primary individuals, who experienced difficulties interacting with their peers, were more likely to experience EST-CS, ‘**anxiety**’ CS, when moving into the secondary CTT. Jane reflected unhappiness during her primary CTT, and all participants shared varying ‘**social**’ CS during their primary CTT. This may be one of the reasons why participants external-vertical transitions into secondary CTT were the most challenging, and this may indicate their need for CSS during this transition, such as ‘***visiting the school***’, ‘***meeting peers and staff***’, as noted by individuals in Hoy et al,[214] a ‘***person-centred plan***’, according to parents in Stoner et al,[221] with CSS in place should difficulties occur as recommended by individuals in Tobias.[222] Prior to starting the secondary CTT, and during the first few weeks of term, Jane was provided with these types of CSS, with access to a special education needs (SEN) provision, something she appeared to greatly benefit from. However, similar to the experiences of an individual in Dillon et al,[204] the school withdrew her support when they realised that Jane did not have an official autism diagnosis.

Mark and individuals, according to parents in Peters et al,[219] shared similar EST-CS, with concerns about the transition into secondary school in relation to the physical size of the school buildings being much bigger and having to mix with a greater number of pupils. Mark and individuals in Makin et al[217] also raised concerns about having to liaise with a greater number of teachers. Worries about their ability to make friends was also shared by participants(Mark, Karen, Andy) and individuals, according to parents in Peters et al.[219]

The transition into and out of sixth form appeared to be a negative experience for some individuals in Hatfield et al.[212] Jane’s experiences of transitioning into sixth form were initially negative but, as discussed in section 4.6.12, this may have been due to her needing a recovery period following her severe ‘**mental health**’ (MH) CS and ES-CS rather than simply being a result of the transition. Prior to the external-vertical transition into the university CTT all participants shared that they received some form of sixth form CSS, such as ‘***the opportunity to learn life skills***’, something individuals in Anderson et al[194] stressed was crucial in order to avoid potential barriers. The majority of participants shared that they received sixth form CSS ‘***applying and preparing for university***’, support making their decision to go to university, as well as administratively, which reflected individuals’ experiences in Mitchell et al.[218] All participants, some individuals in Anderson et al[192] and Anderson et al,[193] shared that their university provided ‘***transitioning***’ CSS such as orientation events, which they described as helpful. In general, ‘***parent***’ CSS appeared to play a crucial role in supporting all participants, throughout all stages of their educational journey, including the transition into university, and the significance of this CSS was highlighted by individuals in Mitchell et al.[218]

Appearing in literature not in research

There was one aspect revealed in the narratives that did not appear in the general literature or literature reviewed.

(1) **Individuals involved in their transition planning**: Individuals (according to parents) in Deacy et al[203] emphasised their experiences of, and the importance of, individuals being involved in their transition planning when moving between educational phases, participants did not share their experiences of this.

6.4.5 Transition support experiences

Day-to-day transition support has been referred to as concurrent stressors support (CSS) throughout this thesis chapter. All participants had day-to-day, internal-horizontal transition needs that required CSS, as noted by individuals in Dixon et al[206] and Peters et al,[219] particularly help in managing changes and uncertainty, as noted by individuals in Van Hees et al.[223] Much of the literature reviewed focused on supporting the needs of individuals transitioning from one educational phase to another.[192-194, 196, 202-204, 212, 214, 217-219, 221, 222, 225] However some literature, such as that of Dillon et al[204] stressed that transition support needed to continue beyond the individuals' first year in their new phase. When putting such support in place, Tobias[222] stated that all transition support should be person centred, and Hoy et al[214] highlighted it should involve having an 'open-door' arrangement to allow parents to raise concerns as they arise and, thus, enabling their involvement as part of the individuals support network.

Commonly, participants,(Jane, Leigh, Andy) individuals in Bottema-Beutal et al[197] and individuals in Dillon et al,[205] had a '***teaching assistant***' (or similar) as CSS, who helped them with their day-to-day academic, emotional-social, transition needs. Some individuals (according to parents) in Dillon et al[204] and Cage et al,[198] had '***peer***' CSS but the literature pointed out that this was not always appropriate particularly when in university and the note taker is your peer.[198] '***Specialist mentors***' became a common positive proactive transition CSS for participants,(Mark, Karen, Jane, Andy) university individuals in Hastwell et al[210] and Anderson et al.[193] Funded in the UK through disabled students allowance (DSA). Leigh, some individuals in Bolourian et al[196] and

Cage et al,[198] didn't have '***specialist mentor***' CSS in place because they refused to apply for DSA as they felt they were not disabled enough to justify it. Participants and many individuals[192, 193, 209, 226] at university also received '***disability/wellbeing service***' CSS, which commonly involved the service helping to set up reasonable adjustments for them, both for exams and when in class. Although again, not all individuals in Gurbuz et al[209] and Anderson et al,[193] chose to access this support. Some individuals in Wiokowski[226] complained about the administration side of things, and some individuals in Anderson et al,[192] complained of delays putting their support in place. Andy was delayed setting up his CSS due to a late diagnosis (in his first year at university), and individuals in Cage et al[198] concurred that it was likely that this type of delay would have exacerbate many of his academic and social disengagement stressors. Finally, the day-to-day sensory transition needs, or '**sensory**' CS, of participants(Jane, Andy) and individuals in Anderson et al,[194] were often supported through the provision of '***sensory free facilities***' CSS, such as '***the cupboard***' for Jane, and a '***quiet space in the school***' for Andy.

6.4.6 Sensory experiences

'**Sensory**' CS were shared by Andy, and were a major ES-CS for Jane, occurring throughout their narratives. As evidenced in this research, by individuals (according to parents) in Cremin et al[202] and Makin et al,[217] as well as in general literature,[8, 24, 52, 53] '**sensory**' CS are common amongst those with autism when in high sensory environments, such as the education setting. As noted in general literature,[64] '**sensory**' CS often results in Ac-CS and ES-CS but, when not supported, it is also believed to be a key factor triggering '**social**' CS. This finding is also supported by the narratives for Jane and Andy. In the general literature, Engel Yeger et al[65] evidenced a relationship between increasing '**sensory**' CS and decreasing abilities to manage daily demands. This also appeared to be the case for Andy, who had to move secondary school due to many factors, including the sensory environment. When placed in a smaller 'safer' private secondary school it was evidenced that Andy's Ac-CS, ES-CS, and '**sensory**' CS reduced significantly and a major improvement was seen in his state of health (MaI).

Jane’s findings demonstrated how she benefited from CSS in the form of a ‘***sensorially free space***’, ‘***the cupboard***’, where she could go when she was feeling overwhelmed due to Ac-CS, ES-CS, and ‘**sensory**’ CS, during her sixth form CTT. An individual in Tobias[222] expressed similar experiences to Jane when Jane’s ‘**sensory**’ CS resulted in challenging behaviours due to lack of CSS. It was evidenced that a direct consequence of negative behavioural reaction to CS, resulted in Jane being labelled by her primary and secondary teachers as a “*problem child*”(P203/00:16:42) rather than considering that she was reacting to autism sensory triggers, reflective of individuals experiences in Cai et al.[199] In common with the findings of individuals in Hastwell et al,[210] Jane also shared that she became overwhelmed during a freshers event due to sensory overload which resulted in a severe meltdown requiring medical assistance. Participants(Mark, Andy) ‘**sensory**’ CS experiences also mirrored those reported by individuals in Hastwell et al[210] who mentioned finding student pubs and nightclubs difficult due to the sensory aspects. Finally, specifically related to learning, participants,(Karen, Jane) individuals in Gurbuz et al[209] and Anderson et al[193] shared how university lecture theatres resulted in auditory challenges for them. Karen, and individuals in Peters et al,[209] found it difficult to process what the lecturers were saying as a result of their ‘**sensory**’ CS. Individuals in Anderson et al[193] emphasised the importance of having reasonable adjustments in place to support difficulties such as a notetaker to transcribe for individuals in lectures.

6.4.7 Change and uncertainty experiences

Difficulties accepting and adapting to change, uncertainties, rather than having the ‘security blanket’ of predictability and structure, were a core difficulty and CS for all participants and individuals in the literature reviewed.[199, 215, 219, 224] Participants(Mark, Karen, Jane) specifically verbalized ‘**change**’ CS, however this does not mean that the other participants did not have ‘**change**’ CS. It is important to note that ‘**change**’ CS has been reflected throughout this chapter in many forms, primarily evident for all participants who, like individuals of Van Hees et al,[224] presented with a need for routine, as well as the context of Ac-CS and ES-CS experiences shared by them throughout their narratives. Pinpointing one CTT as the dominant CTT, when ‘**change**’ CS occurred most frequently for participants was seen as not possible in Cai et al,[199] due to the unquantifiable variables making up these experiences that impacted them directly and indirectly throughout their narratives.

All participants, individuals in Cai et al,[199] Dillon et al[204] and Peters et al[219] indicated that everyday internal-horizontal change CS needed CSS, such as when they changed classrooms, teachers, lectures.[199, 204] Other examples given were the journey to and from school or college,(Karen) breaktimes,(Mark, Jane, Leigh, Andy) and physical education lessons (PE).(Leigh)[219] Participants(Mark, Jane, Leigh, Andy) expressed anxiety relating to their safety at school, which mirrored the anxiety triggers mentioned by individuals in Foulder-Hughes et al.[207] These findings are in support of Maslow's theory,[257] that progression towards 'fulfilment' isn't possible for individuals if they don't feel safe in their educational establishment. Participants(Jane, Andy) shared a common coping mechanism during their secondary CTT when faced with day-to-day '**change**' CS, to go to a quiet place where they could switch off, calm down and feel safe. Parents in Peters et al[219] said that this was also a common coping mechanism used by their children. This again highlights the importance of providing the individual with a quiet-safe place to go, like '***the cupboard***' that Jane was provided with.

The need for day-to-day '***change***' CSS, to support individuals in managing '**change**' CS, and other CS, was evident for all participants at various points in their narrative. CSS appeared to be dependent on and influenced by their mesosystem, exosystem, macrosystem and chronosystem,[255, 256] and played a crucial role in when they received their autism diagnosis, and when they were able to access '***autism specific***' CSS. The parents in Cremin et al[202] stated that the greater the individual's '***autism specific***' CSS, through understanding of their unique characteristics, the happier they appeared to be. In a similar vein, when participants in the current research were provided with '***autism specific***' CSS, there was a notable reduction in their Ac-CS and ES-CS and an overall improvement in all participants state of health. As was seen for Jane, and was noted in general literature,[138] individuals with autism often develop '**self-harming**' CS, as a secondary mental health (MH) condition, when not provided with appropriate '***autism specific***' CSS. Mirroring individuals views in Wiorkowski,[226] some participants(Mark, Karen, Jane) '**change**' CS, and other negative CS experience, did end up resulting in positive, life changing or personal growth, experiences for them.

6.4.8 Independence experiences

Academic independence appeared to increase throughout the educational journey and to result in Ac-CS for all participants, exponentially when they had considerable executive functioning CS, and tending to amplify as independence demands increased, as noted by individuals in Hillier et al.[213] For participants to be equipped for academic and emotional-social independence considerable skills needed to be learnt, and/or taught if they were not naturally acquired. As pointed out in Anderson et al[194] independence skills influenced their individual ability to succeed in their educational journey. Development of these skills was something that Andy struggled with, reducing his independence and, potentially, increasing the CS he experienced.

The external-vertical transition from sixth form CTT to the university CTT appeared to be the greatest independence challenge for participants such as Andy, and individuals in Cage and Howes,[198] because they needed to have greater combination of academic and emotional-social independence skills, without which they felt overwhelmed. Not surprisingly, the dominant CTT when '**living independently**' CS occurred for all participants was during the university CTT. Preparing for university appeared to be the key to all participants overcoming EST-CS, their successful transition into university, as is also evidenced by individuals in Anderson et al,[194] Bolourian et al[196] and Lambe et al.[216] As was seen in Gelbar et al,[208] participants shared how living independently not only necessitated that they learnt independent living skills but also required them to have improved social skills, as social demands also increased at university. As noted by individuals in Gelbar et al,[208] independent practical skills were also needed when living away from home for the first time, cooking, financial budgeting, shopping, and so on. All participants and individuals in Bolourian et al[196] appeared to have independence skills taught to them as part of their sixth form curriculum and/or by family members. Similar to university individuals in Lambe et al,[216] participants(Karen, Jane) expressed being taught independent practical skills, CSS was provided by their '***parent(s)***,(Karen, Jane, Leigh, Andy) and their '***sixth form***'.(Mark, Karen, Jane, Leigh, Andy) There was no mention of specifically designed independent living classes prior to university, as was the case for some individuals in Bolourian et al[196] but some participants(Mark, Karen, Jane, Leigh) did mention attending a transition event run by their university prior to starting.

Similar to individuals in Wiokowski,[226] all participants implied the desire for autonomy, freedom, and independence at university, whether, like individuals in Van Hees et al,[224] with complete independence from parents or a combination of continued support with greater autonomy. For some,(Mark, Jane) living independently at university resulted in a sense of feeling pressurized to change themselves so that they 'socially fit in' with their peers, reflecting individuals in Makin et al[217] and Lambe et al,[216] which was something that participants sometimes struggled to do. Regardless of their state of autonomy, all participants and individuals in Lambe et al[216] continued to have support from their families during their university CTT, particularly when faced with increased social anxiety and pressures to fit in.

6.5 Unique differences and difficulties

This narrative research has enabled participants to not only share the commonalities of having autism but also the unique differences and difficulties experienced. Autistic stereotypes and biases are a likely consequence of people, who are unfamiliar with individuals with autism, who may believe that autistic characteristics fit a generic autism typology. Findings in this research and the literature show that a generic autism typology, does not exist. Although they may share similar CS, every participant in this research, demonstrated a unique personality type with differing characteristics, behavioural responses, and typologies. For example, Mark demonstrated that he had ‘emotionally callous’ characteristics, during his earlier years, which developed and changed into ‘emotionally expressive’ characteristics. Karen, when faced with CS, exhibited ‘resilience’ and ‘perseverance’. As noted in MacGill[264] ‘resilience’ was a key variable that enables adaptability when faced with change and the resultant CS. This was clearly exhibited by Jane and her strength of character appeared to enable her to overcome major ES-CS and MH-CS. She initially positioned herself as ‘a victim’ of her circumstances but later adopting the position of ‘a survivor’. Following her autism diagnosis, she went on to become an ‘agent for positive autistic change’, helping other individuals with autism and those providing CSS to them. Throughout Leigh’s narrative he displayed a passion for wildlife and conservation, which guided and shaped his life choices, resulting in him positioning himself as ‘the champion for wildlife and conservation’. Finally, Andy presented himself throughout his narrative as having a ‘rational, shy, and gentle’ typology.

6.6 Whether findings met expectations

This research successfully met its aim to enable five participants to tell their stories about their unique lived experiences transitioning throughout education. It has given insight into how these participants' experiences relate to the wider autism population and literature. It supports the research expectations that individuals with autism do have transitioning needs, which present as concurrent stressors (CS) during their educational journey and require '***autism specific***' concurrent stressor support (CSS). This use of the combination of narratives and literature, gives a powerful insight into how we might provide better support, and adapt that support, based on the needs of the individual.

6.7 Limitations

This study has limitations. There was a small number of five participants which meant that generalisability was not possible. Although, for narrative research purposes, five participants is on par with the average for other narrative research studies[332-335] and the low numbers are due to the nature of this form of research. Generalisability was also not possible due to the five participants being recruited from the same university (although two went to a different undergraduate university) thus all sharing similar support experiences at this university. This research involved participants self-reporting their educational experiences and this had the potential to limit the quality of data gathered. In conjunction with this, episodic memory difficulties had the potential to result in crucial information being missed, particularly from the early primary years. Parental figure interview data aimed to fill any gaps that might have existed, however, there may have been experiences that parents were not aware of that were important in the context of this research that were not reported. Difficulties with self-understanding and self-conceptualization may have resulted in participants telling a one-sided, potentially biased, story. However, it is important to note that the aim of this research, and the essence of narrative research, was for the participants to share their experiences, even if another's perspective of said experience was different. It follows the premise of this narrative research, if the participant believed an experience was accurate, then this was in fact their truth. Social imagination difficulties, particularly self-reporting experiences, may have resulted in participants not providing the full picture of said experiences in this research. For example, participants may have shared experiences of CS and stated that no CSS was provided, when in fact it was, which may mislead the reader. Also, participants may have made statements such as being '**labelled by the teachers as being a problem child**' CS, which may have been a misconception on the part of the participants, however again it is important to stress that if this was their perception of their experience, regardless of others' perceptions, then this research is a true reflection of their truth.

The researcher (me) being known to the participants, some may argue, devalues data and findings, however I would strongly disagree with this view. My professional background in autism, and professional connection with participants, meant that I had the skills to communicate effectively with them, as well as the ability to interpret subtle non-verbal communication, that might otherwise have been missed. Being known to me may have meant that any social anxiety felt by participants was reduced, something that may have been a barrier if they had been speaking to a stranger, with the potential to limit the story that they shared. Of course, one might argue that participants could have potentially adapted their narrative to meet the ‘perceived aims, needs, wants’ of this research, however, the third triad of social imagination means it was highly unlikely that they would have had the ability to comprehend what these were without me explicitly stating them, which I did not. To ensure that the researcher-participant relationship did not negatively influence the data I rigidly adhered to the methodology, methods, outlined in chapter two. As well as, ensuring that I continued to be mindful of ethics, quality, credibility, confirmability, dependability, transferability, and plausibility throughout.

Using a subjectively derived scoring matrix (section 3.6.6.3, procedural step 4), which attempts to quantify qualitative data, has the potential to result in theoretical bias and limitations within the research. It is important to stress to the reader that the aim of the scoring matrix in this research was not to quantify qualitative participant experiences but to “*operationalize one’s subjective impression by coding the verbal evidence for that impression and comparing the frequencies of the codes quantitively*”.[350(p282)] The scoring matrix formulated subjectively derived frequency values to a participant’s CS experience, linguistic tones, and state of health during a CTT. These frequencies of coded qualitative values were calculated in a quantifiable manner through the scoring matrix as a means to compare the qualitative data, with the aim of enhancing the readers insight and understanding about each participants’ experience of CS and their state of health during each CTT.

Chapter 7: Conclusion

7.1 Recommendations

7.1.1 Contribution to knowledge

Based on the findings in this research and related literature, I have made recommendations of areas that require further exploration (table 7.1). The overriding reasoning behind these recommendations is to further enhance others' understanding about individuals (with autism) transitioning needs, as well as increase the educational establishment's understanding. With the ultimate aim of providing greater insight into person-centred concurrent stressors (CS) and concurrent stressor support (CSS) needs, enabling all individuals to reach their full academic, emotional-social and life potential.

Table 7.1: Summary of the specific areas of research that have been identified by this research that require further exploration of individuals' experiences in education with a focus on the 'higher functioning' autistic population.

Area requiring further exploration within the educational system
The effectiveness and efficacy of concurrent stressor support provisions provided to individuals in education • ***Explore:*** What CSS support is currently being provided to individuals during each CTT, to gather specific data about this CSS, detailing who it is provided by, how effective and efficacious it is. • ***Aim:*** To provide effective and efficacious CSS that best meets individual's unique needs.
Experiences prior to receiving their autism diagnosis and the academic, emotional-social, impact that 'being undiagnosed' (with autism) has on an individual • ***Explore:*** Individual's experiences prior to receiving their autism diagnosis, to gather data on how long this process takes, the Ac-CS and ES-CS impact that this had on the individual.(1) The experiences of 'higher functioning' autism population, the impact that '**being undiagnosed**' (with autism) has in terms of CS, and the impact that lack of CSS has on them. (2) The referral process, time frames, Ac-CS and ES-CS impact. • ***Aim:*** To provide insight into the early signs of 'higher functioning' 'individuals and their referral for assessment. Provide effective and efficacy CSS that meets their unique Ac-CS and ES-CS needs prior to and following diagnosis.
How individuals hide their autism, different types of masking and the impact this has on self-concept • ***Explore:*** The reasoning behind individuals who do not want to 'draw attention to self', how they went about doing this, types of masking, the effect that this had on their self-concept, and mental health. • ***Aim:*** To provide insight into types of masking, why it might happen, how often, the effects of masking on the individual, CSS needs, in order to reduce secondary mental health conditions.
Factors that result in individuals' experiencing social exhaustion • ***Explore:*** What factors trigger social exhaustion. • ***Aim:*** To provide insight into potential social exhaustion triggers and provide person centred CSS.
Whether the current UK examination format and system meets the needs of individuals or requires further reasonable adjustments • ***Explore:*** Individuals' experiences of the UK exam system and formatting. (1) The style of exam questioning, e.g., abstract nature, non-specific. (2) The flow of exam questioning, e.g., whether their formatting makes it difficult to easily move on to the next question when stuck, due to rigid, inflexible thinking. (3) Reasonable adjustments, e.g., 25% extra time, whether this is sufficient. • ***Aim:*** To provide insight into exam specific CSS that meets individual's needs, e.g., individuals needing to be taught 'exam skills' related to their differences and difficulties, skills which they may not have naturally acquired when compared with their peers.
The impact that messaging and communication has on individuals within an educational and family setting • ***Explore:*** Messaging and communication used by schools, colleges, universities, and the impact that this has on an individual, e.g., when an educational provider emphasises the need to get high grades, complete certain examination to succeed. • ***Aim:*** To provide insight into appropriate messaging and communication which reduces potential exacerbation of individuals stress levels due to their fixed mindset, lack of flexibility, literal interpretation of speech, and inability to rationalize statements.
Different forms of bullying experienced by individuals in each educational phase and the link between bullying and secondary mental health conditions. • ***Explore:*** Frequency of bullying and forms within all educational phases. • ***Aim:*** To provide insight into types of bullying during each educational phase and CSS needs.
Co-occurring PTSD and susceptibility amongst the autistic population • ***Explore:*** Whether a relationship exists between autism and PTSD, identifying susceptibility factors. • ***Aim:*** To provide insight into the relationship between PTSD and autism, and CSS needs.
Continuation of restricted repetitive behaviours (RRB) in university individuals, including Eating disorders (ED) and PICA. • ***Explore:*** Types of restricted repetitive behaviours (RRB) presenting in university individuals • ***Aim:*** To provide insight into restrictive repetitive behaviours (RRB) in university individuals and their CSS needs.
UK university individuals' experiences of concurrent stressor support provisions • ***Explore:*** The effectiveness and efficacy of university individuals CSS provisions • ***Aim:*** To provide insight into effective and efficacious CSS provided to university 'individuals.

7.1.2 Practical implications

The findings from this research thesis and literature (general and reviewed), as summarised in figure 7.1, clearly highlight that individuals face considerable CS, during their day-to-day transitions and when transitioning into a new educational phase. The practical implications of these findings have resulted in materials that can be used by researchers in this field, persons who support individuals and for individuals themselves.

7.1.2.1 The change-transitioning model (for researchers)

The 'change-transitioning model (for researchers)' figure 7.2 is a reformatted version of the 'educational transitioning model' (figure 3.9). A methodological framework that researchers can use to investigate the change-transitioning needs of research participants. The step-by-step approach consists of a researcher identifying:

(1) Any major and/or minor CS. If the researcher is investigating individuals with autism they can use figure 7.1, as a guide to potential CS during an educational journey, based on the findings in this thesis.

(2) Self-characteristics (e.g., concept, ego, esteem) that potentially positively or negatively influence a participant's ability to adapt to a change-transition, such as; whether they are undiagnosed with any neuro-diverse conditions, 'others' perceptions of them (e.g., stereotypes or discrimination that might be impacting them) and any coping strategies, or skills, that they might have that potentially influences their ability to take control and/or manage any CS (e.g., resilience).

(3) Participant's CSS and support in general, that potentially positively or negatively influences their ability to adapt to a change-transition and manage any CS. Table 7.2 illustrates the different types of CSS support and CSS providers in relation to the findings in this thesis, which researchers can consider when investigating change-transitioning CSS provisions, such as; (i) stable positive CSS, which is efficacious, resulting in the reduction of CS or elimination of CS, (ii) unstable positive CSS, which is likely to be efficacious, resulting in the reduction of CS and/or preventing a further increase of CS, (iii) unstable negative CSS, resulting in the continuation of CS or an

increase in CS. Finally, (iv) considers the impact of no CSS provision(s) and whether this resulted in a continuation of CS or an increase in CS.

(4) A participant's state of health and their ability to adapt to a change-transition by calculating if there has been a major deterioration (MaD), minor deterioration (MiD), major improvement (MaI) or minor improvement (MiI) in overall state of health. State of health is calculated by considering state of health in a previous change-transition phase minus state of health in a current change-transition phase, based on CS experiences, the positive or negative influence of 'self' characteristics and/or CSS provisions, as illustrated in figure 7.2.

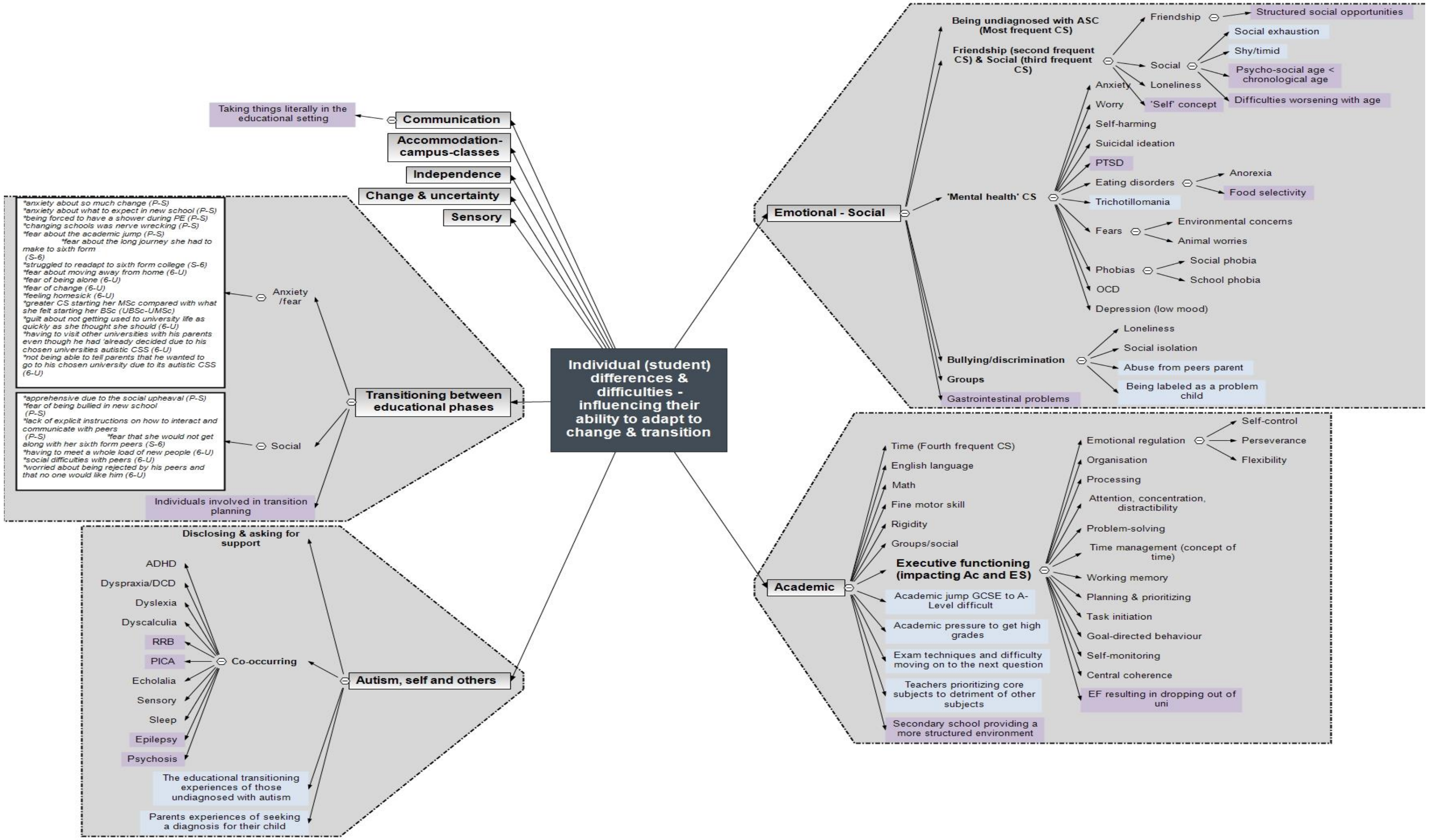
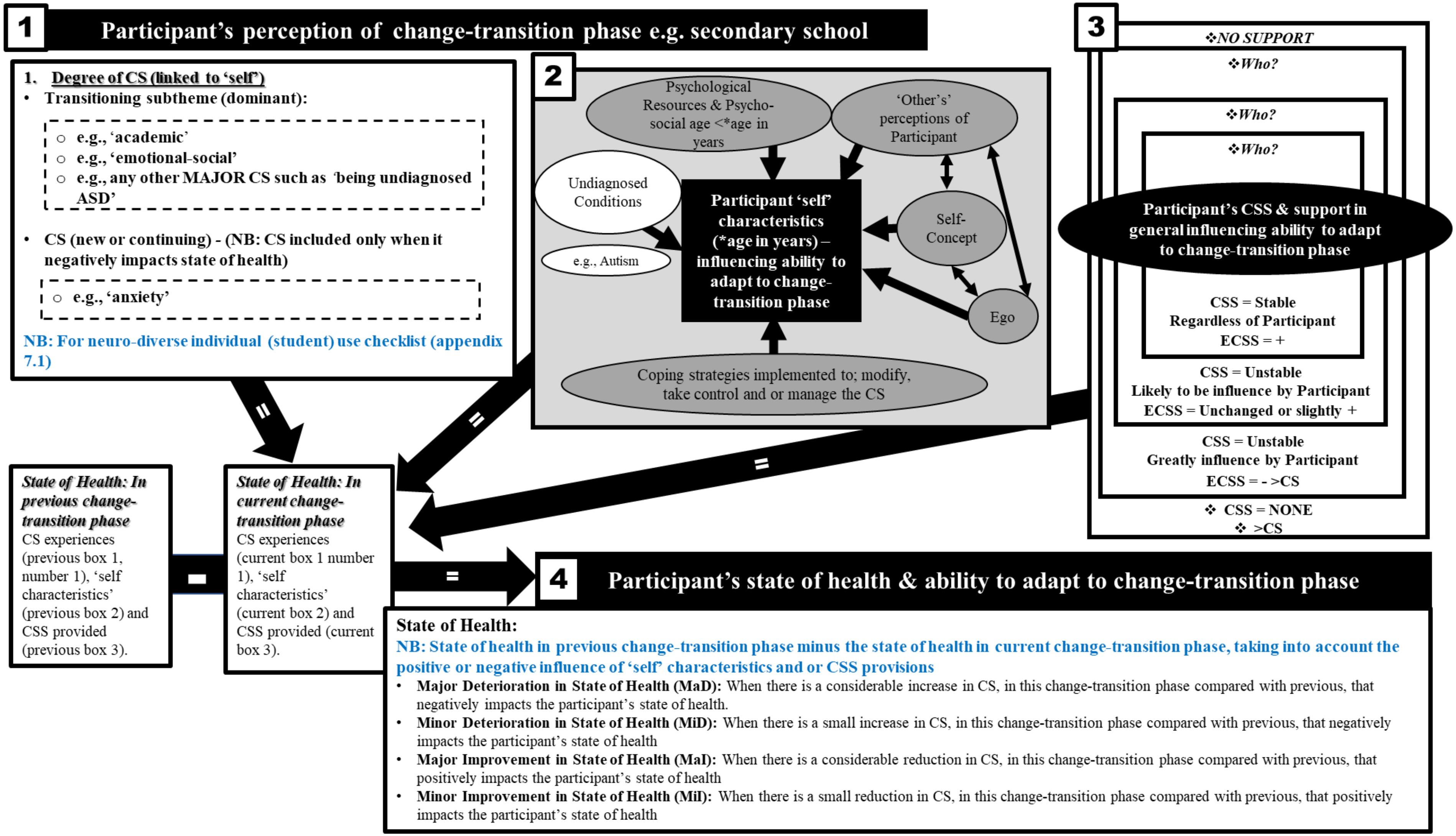


Figure 7.1: A summary of the characteristics and co-occurring conditions that occur in individuals (students) with autism, in research and literature (general and reviewed), that impact their ability to adapt to change and transition. Grey = appearing in both research and literature. Light blue = appearing in research not in literature. Purple = appearing in literature not in research.

Table 7.2: Summary of types of concurrent stressor support (CSS), the influence that this has, impact on concurrent stress (CS), effectiveness, efficacy, and examples of CSS.

	(i) Stable Positive CSS	**(ii) Unstable Positive CSS**	**(iii) Unstable Negative CSS**	**(iv) No CSS**
Influence of participant on type of support	Regardless of behaviour or circumstances	Likely to be influenced by behaviour or circumstances	Greatly influenced by behaviour or circumstances	Could be influenced by participant e.g., if did not meet the criteria for CSS
Potential impact of CSS on CS	Reduction in CS	Reduction in CS or CS remaining unchanged	Resulting in a potential increase in CS	Resulting in a potential increase in CS
Potential effectiveness and longer-term efficacy of CSS	Positive	Positive to neutral (dependent on longer-term effectiveness and/or how long the CSS continues)	Negative effectiveness and efficacy	n/a
Examples of primary school CSS	Books (who were best friends) Close family Parent(s) Private tutor SEN unit Sibling(s)	Close friends Smaller learning groups Supportive teachers Teaching assistant	'Other' peers Unsupportive headteachers/ teachers	*
	Reasonable adjustments in educational phase			
Examples of Secondary school CSS	Books (who were best friends) Parent(s) Private tutor Sibling(s)	Close friends Friends from previous school SEN unit Smaller classes Student support services Supportive teachers	'Other' peers Unsupportive teachers	*
	Reasonable adjustments in educational phase			
Examples of Sixth form or College CSS	Autism centre Parent(s) Private tutor	Autism trained staff Close friends Student support services Supportive teachers/ head of year	'Other' peers Unsupportive teachers	*
	Reasonable adjustments in educational phase			
Examples of University CSS	Best friend Boyfriend/ girlfriend Close family member Parent SEN unit	Autism specific service Close friends Counselling service Disability/Wellbeing services GP NHS services Societies and social groups Specialist mentor/tutor (through DSA) Supportive external agencies Supportive lecturers, mentors, tutors Supportive teaching assistant	'Other' peers Bullies/ people being bitchy Peers who didn't understand autism Unfriendly peers Unsupportive lecturers, mentors, tutors	*
	Reasonable adjustments & SEN provisions in educational phase			

* CSS provisions that are not available to participant due to not having a medical diagnosis.



1 **Participant's perception of change-transition phase e.g. secondary school**

1. **Degree of CS (linked to 'self')**

- **Transitioning subtheme (dominant):**
  - **e.g., 'academic'**
  - **e.g., 'emotional-social'**
  - **e.g., any other MAJOR CS such as 'being undiagnosed ASD'**
- **CS (new or continuing) - (NB: CS included only when it negatively impacts state of health)**
  - **e.g., 'anxiety'**

NB: For neuro-diverse individual (student) use checklist (appendix 7.1)

2

Psychological Resources & Psycho-social age <*age in years

'Other's' perceptions of Participant

Undiagnosed Conditions

e.g., Autism

Participant 'self' characteristics (*age in years) – influencing ability to adapt to change-transition phase

Self-Concept

Ego

Coping strategies implemented to; modify, take control and or manage the CS

3

❖*NO SUPPORT*

❖*Who?*

❖*Who?*

❖*Who?*

Participant's CSS & support in general influencing ability to adapt to change-transition phase

CSS = Stable
Regardless of Participant
ECSS = +

CSS = Unstable
Likely to be influence by Participant
ECSS = Unchanged or slightly +

CSS = Unstable
Greatly influence by Participant
ECSS = - >CS

❖ **CSS = NONE**
❖ **>CS**

State of Health: In previous change-transition phase
CS experiences (previous box 1, number 1), 'self characteristics' (previous box 2) and CSS provided (previous box 3).

–

State of Health: In current change-transition phase
CS experiences (current box 1 number 1), 'self characteristics' (current box 2) and CSS provided (current box 3).

=

4 **Participant's state of health & ability to adapt to change-transition phase**

State of Health:

NB: State of health in previous change-transition phase minus the state of health in current change-transition phase, taking into account the positive or negative influence of 'self' characteristics and or CSS provisions

- **Major Deterioration in State of Health (MaD):** When there is a considerable increase in CS, in this change-transition phase compared with previous, that negatively impacts the participant's state of health.
- **Minor Deterioration in State of Health (MiD):** When there is a small increase in CS, in this change-transition phase compared with previous, that negatively impacts the participant's state of health
- **Major Improvement in State of Health (MaI):** When there is a considerable reduction in CS, in this change-transition phase compared with previous, that positively impacts the participant's state of health
- **Minor Improvement in State of Health (MiI):** When there is a small reduction in CS, in this change-transition phase compared with previous, that positively impacts the participant's state of health

Figure 7.2: The change-transitioning model (for researchers). Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

7.1.2.2 The educational transitioning model (for support persons)

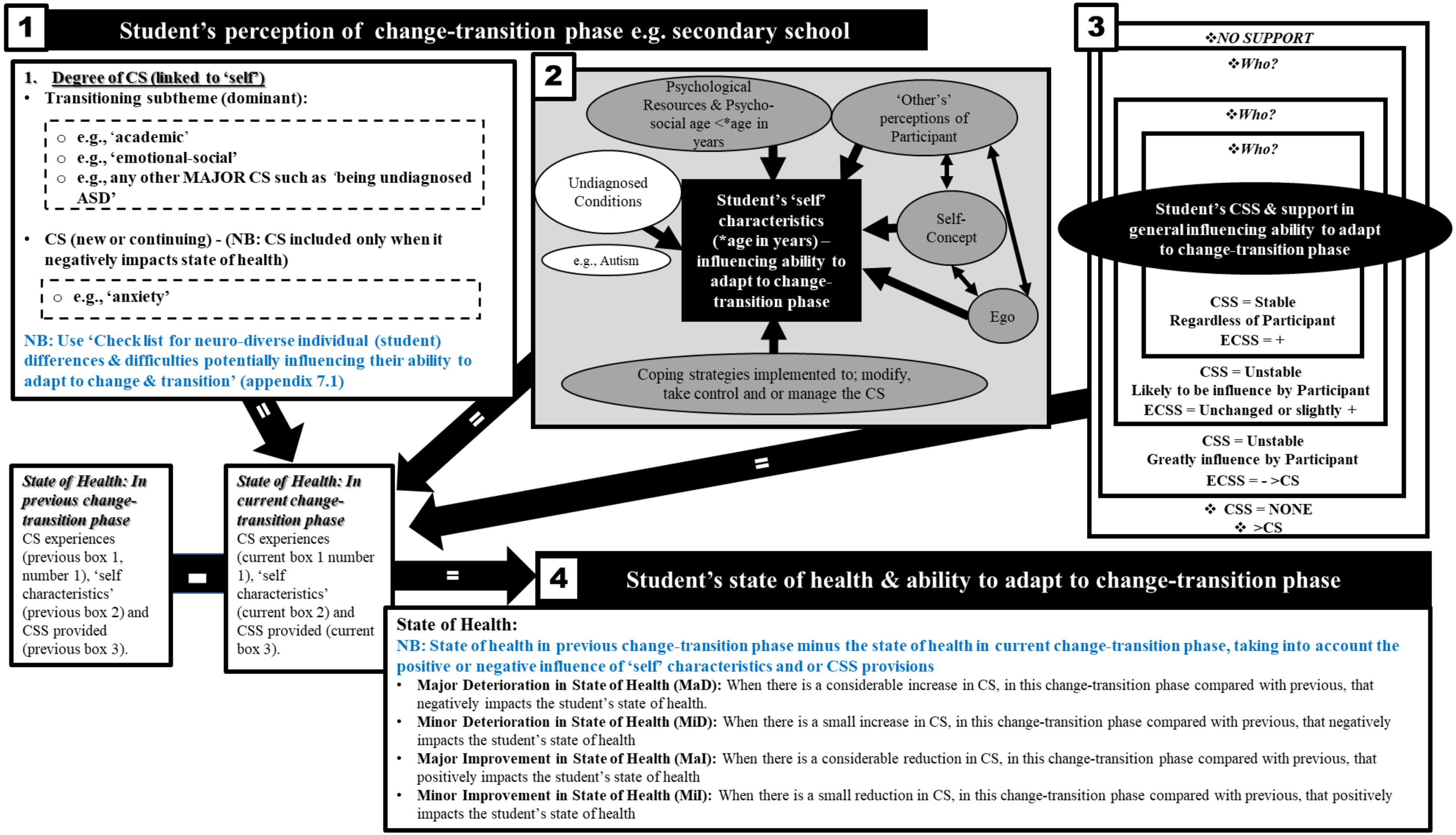
The ‘educational transitioning model (for support persons)’ figure 7.3 is a reformatted version of the ‘educational transitioning model’ (figure 3.9). A methodological framework that support persons can use when investigating the transitioning needs of neuro-diverse students. The step-by-step approach consists of a support person identifying:

(1) Any major and/or minor CS. If the support person is supporting an individual with autism they can use figure 7.1, as a guide to potential CS during an educational phase, based on the findings in this thesis.

(2) Self-characteristics (e.g., concept, ego, esteem) that potentially positively or negatively influence a student’s ability to adapt to a change-transition, such as; whether they are undiagnosed with any neuro-diverse conditions, ‘others’ perceptions of them (e.g., stereotypes or discrimination that might be impacting them) and any coping strategies, or skills, that they might have that potentially influences their ability to take control and/or manage any CS (e.g., resilience).

(3) The student’s CSS and support in general, that potentially positively or negatively influences their ability to adapt to a change-transition and manage any CS. As detailed in table 7.2 the support person can consider whether the CSS provided is; (i) stable positive CSS, which is efficacious, resulting in the reduction of CS or elimination of CS, (ii) unstable positive CSS, which is likely to be efficacious, resulting in the reduction of CS and/or preventing a further increase of CS, (iii) unstable negative CSS, resulting in the continuation of CS or an increase in CS. Finally, (iv) considers the impact of no CSS provision(s) and whether this results in a continuation of CS or an increase in CS.

(4) A student’s state of health and their ability to adapt to a change-transition by calculating if there has been a major deterioration (MaD), minor deterioration (MiD), major improvement (MaI) or minor improvement (MiI) in overall state of health. State of health is calculated by considering state of health in a previous change-transition phase minus state of health in a current change-transition phase, based on CS experiences, the positive or negative influence of ‘self’ characteristics and/or CSS provisions, as illustrated in figure 7.2.



Student's perception of change-transition phase e.g. secondary school

1. **Degree of CS (linked to 'self')**
- **Transitioning subtheme (dominant):**
    - **e.g., 'academic'**
    - **e.g., 'emotional-social'**
    - **e.g., any other MAJOR CS such as 'being undiagnosed ASD'**
- **CS (new or continuing) - (NB: CS included only when it negatively impacts state of health)**
    - **e.g., 'anxiety'**

NB: Use 'Check list for neuro-diverse individual (student) differences & difficulties potentially influencing their ability to adapt to change & transition' (appendix 7.1)

Psychological Resources & Psycho-social age <*age in years

'Other's' perceptions of Participant

Undiagnosed Conditions

e.g., Autism

Student's 'self' characteristics (*age in years) – influencing ability to adapt to change-transition phase

Self-Concept

Ego

Coping strategies implemented to; modify, take control and or manage the CS

❖*NO SUPPORT*

❖*Who?*

❖*Who?*

❖*Who?*

Student's CSS & support in general influencing ability to adapt to change-transition phase

CSS = Stable
Regardless of Participant
ECSS = +

CSS = Unstable
Likely to be influence by Participant
ECSS = Unchanged or slightly +

CSS = Unstable
Greatly influence by Participant
ECSS = - >CS

❖ **CSS = NONE**
❖ **>CS**

State of Health: In previous change-transition phase
CS experiences (previous box 1, number 1), 'self characteristics' (previous box 2) and CSS provided (previous box 3).

State of Health: In current change-transition phase
CS experiences (current box 1 number 1), 'self characteristics' (current box 2) and CSS provided (current box 3).

Student's state of health & ability to adapt to change-transition phase

State of Health:

NB: State of health in previous change-transition phase minus the state of health in current change-transition phase, taking into account the positive or negative influence of 'self' characteristics and or CSS provisions

- **Major Deterioration in State of Health (MaD):** When there is a considerable increase in CS, in this change-transition phase compared with previous, that negatively impacts the student's state of health.
- **Minor Deterioration in State of Health (MiD):** When there is a small increase in CS, in this change-transition phase compared with previous, that negatively impacts the student's state of health
- **Major Improvement in State of Health (MaI):** When there is a considerable reduction in CS, in this change-transition phase compared with previous, that positively impacts the student's state of health
- **Minor Improvement in State of Health (MiI):** When there is a small reduction in CS, in this change-transition phase compared with previous, that positively impacts the student's state of health

Figure 7.3: The Educational Transitioning Model (for support persons). Adapted from:[255-259, 263-268] For abbreviations see chapter three, table 3.4.

7.1.2.3 Neuro-diverse guide for support persons

My (the researcher's) ultimate objective from this research was to use the information discovered to go on to produce a guide: 'Educational Transitions. A guide to best practice: Supporting neuro-diverse students' transitions into a new educational phase and with their day-to-day needs' (content illustrated in appendix 7.2). This guide will provide those who are supporting neuro-diverse students with information to gain a greater understanding about these students unique needs, any CS being experienced by them and enable them to provide appropriate CSS. Those likely to be supporting students, includes '***parents***', '***carers***', '***teachers***', '***headteachers***', '***teaching assistants***' (TA), '***learning support assistants***' (LSA), '***specialist educational needs co-ordinators***' (SENCO), '***additional learning needs co-ordinators***' (ALNCo), '***educational psychologists***', and any other '***member of staff working with a neuro-diverse student'***. Thus, this multifaceted guide will provide the support person with in-depth information about the unique differences and difficulties facing a neuro-diverse student and strategies that will enable them to support these students in reaching their full potential academically, emotionally-socially, and with everyday life skills. An outline of what is proposed for each section is given below:

Introduction

This section details definitions, background information and the aim and ethos of the guide, which is to improve the support person's understanding about neuro-diverse students and to enable these students to reach their full potential.

The Educational Transitioning Model (for support persons)

This section introduces the model (as discussed in section 7.1.2.2, figure 7.3) as a tool that can be used to identify the student's: (1) Unique CS experiences, (2) Self characteristics in managing CS and areas where this could be improved, (3) Current types of CSS support provided and areas where this could be improved. (4) Ability to adapt to their new educational environment, in relation to their proposed state of health, e.g., by considering how improvements in areas 1-3 have the potential to result in an improvement in overall state of health.

Being a neuro-diverse student

This section considers what being neuro-diverse means, how to spot the signs of co-occurring conditions such as; Autism/ASD (Autism Spectrum Disorder), ADHD (Attention Deficit Hyperactive Disorder), Anxiety disorders, Dyspraxia/DCD (Development Co-ordination Disorder), Dyslexia, Dyscalculia, OCD (Obsessive Compulsive Disorder). It highlights the importance of early referral, students disclosing their neuro-diverse condition(s) and of person-centred support. Concluding with why day-to-day change-transitions and the external-vertical change-transitions into a new educational phase might be difficult.

Enabling a student to understand their unique differences and difficulties

This section focuses on the support person being equipped with the information to enable a neuro-diverse student to understand their unique differences and difficulties as well as the positives of being neuro-diverse. Topics covered include: (1) Academic and executive functioning, focusing on learning preferences and unique executive functioning needs. (2) Behaviour, focusing on empathetically connecting with the student and encouraging positive behaviour change. (3) Change and Transition, focusing on how change impacts performance and how to enable a student to manage new things. (4) Communication, focusing on communication preferences. (5) Emotional-social, focusing on emotional regulation, self (e.g., awareness, control, esteem), perseverance, resilience, flexibility, and social skills. (6) Independence, focusing on academic independence, emotional-social independence, day-to-day living skills, day-to-day health skills. (7) Mental health, focusing on anxiety, depression, eating disorders, fears, phobias, obsessions-rituals-routines, obsessive compulsive disorder (OCD), post-traumatic stress disorder (PTSD), self-harming, suicidal ideation, worries. (8) Sensory, focusing on sight, sound, smell, taste, touch and texture, proprioceptive system, vestibular system, interoceptive system.

Primary, secondary, sixth form or college

These sections focus on: (1) Supporting the transition into a new educational phase. (2) Support available during these phases, (i) what a neuro-diverse student is entitled to because of their condition(s), such as reasonable adjustments in exams, reasonable adjustments with learning, disability support, mental health support. (3) Ongoing day-to-day support needs during an educational phase, focusing on differences and difficulties relating to academic and executive functioning, behavioural, change and transition, communication, emotional-social, independence, mental health, and sensory.

University

This section specifically focuses on: (1) Supporting the transition into university, emphasising the importance of the student learning skills in relation to independent living, administration, daily living, money management, health and wellbeing, and time management. (2) Support available at university, (i) the importance of disclosing and asking for support, (ii) what a neuro-diverse student is entitled to because of their condition(s), such as reasonable adjustments in exams, reasonable adjustments with learning, disability support, mental health support, ‘Disabled Student Allowance’ (DSA) (iii) additional support all students can access at university. (3) Ongoing day-to-day support needs in university, focusing on differences and difficulties relating to academic and executive functioning, behavioural, change and transition, communication, emotional-social, independence, mental health, and sensory.

7.1.2.4 Neuro-diverse guides for individuals and their families

In conjunction with the support persons guide, two complimentary guides will encompass this aforementioned information and will be produced for the neuro-diverse student and their families. (1) ‘Preparing for secondary school or sixth form: Managing your transition into a new educational phase and your day-to-day needs’ (content illustrated in appendix 7.3) and (2) ‘Preparing for university: Managing your transition into university and your day-to-day needs’ (content illustrated in appendix 7.4).

These multifaceted guides will provide the individual with in-depth information about their unique differences and difficulties as a neuro-diverse student and strategies that will enable them to reach their full potential academically, emotionally-socially, and with everyday life skills. An outline of what is proposed for each section is given below:

Introduction

This section details definitions, background information and the aim and ethos of the guide, which is to improve the individual's understanding about neuro-diversity and to enable them to reach their full potential.

Being a neuro-diverse student

This section considers what being neuro-diverse means, how to spot the signs of co-occurring conditions such as; Autism/ASD (Autism Spectrum Disorder), ADHD (Attention Deficit Hyperactive Disorder), Anxiety disorders, Dyspraxia/DCD (Development Co-ordination Disorder), Dyslexia, Dyscalculia, OCD (Obsessive Compulsive Disorder). It highlights the importance of early referral, disclosing their neuro-diverse condition(s) and of person-centred support. Concluding with why day-to-day change-transitions and the external-vertical transitions into a new educational phase might be difficult.

Understanding your unique differences and difficulties

This section will provide the individual with the information that they need to be able to understand their unique differences and difficulties as well as the positives of being neuro-diverse. Topics covered include: (1) Academic and executive functioning, focusing on learning preferences and unique executive functioning needs. (2) Behaviour, focusing on empathetically connecting with an individual and encouraging positive behaviour change. (3) Change and Transition, focusing on how change impacts performance and how to enable an individual to manage new things. (4) Communication, focusing on communication preferences. (5) Emotional-social, focusing on emotional regulation, self (e.g., awareness, control, esteem), perseverance, resilience, flexibility, and social skills. (6) Independence, focusing on academic independence, emotional-social independence, day-to-day living skills, day-to-day health skills. (7) Mental health, focusing on anxiety, depression, eating disorders, fears, phobias, obsessions-rituals-routines, obsessive compulsive disorder (OCD), post-traumatic stress disorder (PTSD), self-harming, suicidal ideation, worries. (8) Sensory, focusing on sight, sound, smell, taste, touch and texture, proprioceptive system, vestibular system, interoceptive system.

Secondary, sixth form or college, university

These sections focus on the particular educational phase: (1) Support transitioning into a new educational phase. (2) Support available during an educational phase, (i) the importance of disclosing and asking for support, (ii) what neuro-diverse individuals are entitled to because of their condition(s), such as reasonable adjustments in exams, reasonable adjustments with learning, disability support, mental health support. (3) Ongoing day-to-day neuro-diverse support needs during an educational phase, particularly differences and difficulties relating to academic and executive functioning, behavioural, change and transition, communication, emotional-social, independence, mental health, and sensory.

Please note: The ‘Preparing for university: Managing your transition into university and your day-to-day needs’ guide, goes into additional specific detail about: (1) Support transitioning into university, focusing on the importance of neuro-diverse individuals learning skill such as, independent living, administration, daily living, money management, health and wellbeing, and time management. (2) Support available at university, (i) the importance of disclosing and asking for support, (ii) what being a neuro-diverse student entitles you to because of your condition(s), such as reasonable adjustments in exams, reasonable adjustments with learning, disability support, mental health support, ‘Disabled Student Allowance’ (DSA), (iii) additional support all students can access at university. (3) Ongoing day-to-day support needs in university, focusing on differences and difficulties related to academic and executive functioning, behavioural, change and transition, communication, emotional-social, independence, mental health, and sensory.

7.2 Conclusions

This research has informed readers about the unique needs that individuals with autism have. It has provided detailed information that can be put into practice to help break down barriers, reduce discrimination and improve the lives of said individuals. In doing so, it will help facilitate each individual to reach their full potential.

The experiences shared clearly shaped individuals' reality, their self-identity formation, particularly disabling ES-CS experiences. All participants demonstrated unique autism profiles, with varying typologies, mirroring literature (general and reviewed) relating to the autistic population. This research and literature both evidenced that individuals had difficulties disclosing their autism, asking for support, and that individuals had a variety of co-occurring conditions. This research touched on '**being undiagnosed with ASC**' CS, as well as the negative parental experiences of seeking an ASC diagnosis for their child, which the literature did not.

Participants internal-horizontal, day-to-day transitioning experiences, CS, CSS, have been identified for each educational phase. The five participants' narratives may present a microscopic snapshot from the much larger autistic perspective but these 'first person narratives', when compared with literature, clearly illustrate important key points (figure 7.1). Individuals have Ac-CS and ES-CS throughout all stages of their educational journey, with an escalation in both types of stressors during the secondary educational phase. The most prevalent CS participants experienced were, in order of most dominant CS, '**being undiagnosed with ASC**', '**friendship**', '**social**' and '**time**'. In addition, specific ES-CS experiences that were mentioned in both this research and literature were bullying, discrimination, loneliness, social isolation, and social groups. Participants and individuals in literature noted ES-CS specifically relating to mental health (MH), anxiety, worry, self-harming, suicidal ideation, eating disorders, fears, phobias, OCD, and depression. This research also raised MH-CS experiences of trichotillomania, which was not discussed in literature.

Specific Ac-CS experiences mentioned by participants and in literature were '**time'** CS (the fourth most frequent CS), followed by (not in order of frequency) '**English language**', '**math**', '**fine motor skills**', '**rigidity**', difficulties with academic groups and a wide range of executive functioning difficulties. The academic jump from GCSE to A-Levels, academic pressure to get high grades, difficulties in exams with moving on to the next questions, and teachers who prioritised core subjects to the detriment of other subjects, were all Ac-CS shared by participants, which were not discussed in literature.

The participants external-vertical transitions between educational phases resulted in emotional-social transitioning concurrent stressors (EST-CS), which required emotional-social transitioning concurrent stressor support (EST-CSS), mirroring the findings in literature. Some literature focused on individuals' experiences of transition planning; however, this was not addressed in this research by the participants. Overall, the EST-CS and EST-CSS provided was greatest for participants during their transition between the sixth form and university phase.

Other ES-CS experiences that appeared in research and literature were sensory CS, change and uncertainty CS, and independence CS.

To minimise a deterioration in state of health and improve educational, academic, emotional-social, experiences, all CS required specialist ASC understanding, as well as individuals having a diagnosis of ASC, in order for them to be able to receive efficacious autism specific CSS. This research demonstrated that the secondary educational phase proved the most challenging for all participants with the greatest overall CS, a major deterioration in state of health and regression in all narratives. Lack of ASC diagnosis, which is commonly reported in 'higher functioning' individuals,[78-80, 348, 349] appeared to be a major reason for lack of autism specific CSS for all participants (with the exception of one) during the secondary CTT. This supports the argument for early referral, assessment, and diagnosis, as well as the need to encourage and support the individual awaiting an assessment with their presenting needs and their parent(s) through that process.

It is evident that a diagnosis and provision of autism specific CSS, as was the case for all participants during the university phase, does not always guarantee a reduction in, or elimination of, CS and improvement in state of health, due to core autistic features such as co-occurring depression, obsessive phobias, and inescapable social difficulties, which require ongoing CSS. Thus individuals, their parents, their educational establishments, and autism specific services all need to work together to ensure individuals understand their autism and are understood by others. Any support plans that are produced need to be regularly reviewed and evolve with the individual's developmental needs. This will, hopefully, lead to them getting the most efficacious CSS in place, being accepted by others and being comfortable within their place of study and, thus, will maximise their chances of reaching their full potential.

Finally, it is vital to conclude this thesis by highlighting the remarkable achievements of every participant. Even though each participant presented with unique qualities a commonality that they shared was determination, resilience, and strength of character, when faced with often-overwhelming concurrent stressors and barriers. Mark's narrative illustrated a growth in his self-advocacy skills, his ability to express his emotions, feelings, and his ability to understand the emotions of others, and how this resulted in an overall growth in self-confidence. Mark described how he positively evolved from an 'emotionally callous' individual into an 'emotionally expressive' one. Karen demonstrated resilience throughout her narrative, an innate strength whereby she was able to optimistically persevere regardless of the CS challenges facing her, to not give up but continue to proactively embrace opportunities to interact with others emotionally-socially. Jane's narrative evolved dramatically, initially presenting with a 'victim' typology, when faced with a large number of emotional-social and mental health CS, then later able to overcome these CS, after being diagnosed, receiving specialist support, and improved self-advocacy skills. Jane became the 'hero' of her story, an 'agent' of positive change not only in her world but also in the autistic world, helping others who had autism. Throughout Leigh's narrative he demonstrated courage and determination when faced with CS. In his earlier years he described himself as a 'fish out of water', due to being very different from his peers. In Leigh's later years his courage, determination, resilience, self-advocacy skills, and passion for wildlife, enabled him to overcome most of his CS. Similar to Jane, Leigh became the 'hero' in his narrative, pursuing his passion and becoming 'the champion of wildlife and conservation'. Andy's narrative demonstrated that he managed CS with a logical, rational, reasoned, and sensible approach. His intelligence enabled him to achieve academic success, passing his law degree, and his gentle, affable, peaceful nature enabled him to achieve emotional-social success, through a growth in his self-acceptance, self-understanding, and ability to form friendships.

The overriding life changing realisation shared by all participants in this thesis was the moment that they understood why they were different, why they experienced difficulties, because they were autistic. This moment of enlightenment appeared to result in ‘a weight being lifted from their shoulders’, a sense of relief, and a breakthrough in terms of their self-awareness, self-acceptance, and self-advocacy skills.

Appendices

Appendix 2.1: Exclusion of irrelevant papers following advance search results, prior to data extraction

Category	Method	Exclusion criteria
Exclusion criteria words	Search in excel based on using 'find' to identify exclusion words in title	**Words**: Mentor, LGBT/LGBTQ, geoscientists, intervention, model, employ*, preschool, coach*, Sexual*, management, special school-education, diagnos*, behavior analysis, intellectual dis, quantitative, parent strategies, learning disabil*, severity, quantitative, comparison (unless suitable), guide, parent or teacher (unless in conjunction with student), teach, work, (social) stories, virtual, guardian*, assessment, therapy, supporting family, others perception, biology, attitude towards, tasks, Egypt, programs, caregiver, maternal, toolkits, Japanese, Ghana, Saudi
Exclusion criteria terminology	Search the gist of the research paper's title to identify exclusion terminology	**Terminology:** not specifically related to student with autism experiences, and/or when focused explicitly on another topic e.g., support services, school exclusions, college accessibility, prevalence, others openness to ASD, inclusion programs, not student voice, demand avoidant behaviour, cultural stigma, gender dysmorphia, diagnosis, gifted students, healthcare, best practice, rural community, alexithymia, decision making, interventions, MMR, educational decision making, analysis of practice, a guide, approaches, predictors of, out of school activities, solely observation, physical educ, profiles, promotion of, therapy, race, bi-lingual, peer support-learning, project, experiment, traits, quotients, phenotype, family dynamics, research recommendations
Excluded based being too specific	Search the research paper's title to identify if paper is too specific and not relating to general experiences	**Specification:** when title relates to specific field or topic and is not relating to broader educational experiences. Such as, reasonable adjustments, peer support, social relationships, bullying and identity development, functioning and participation problems, inclusion, social relations and social support, social networks and friendships, college readiness, comparison to neurotypicals, understanding and valuing communication, factors affecting completion of degree, art if camouflaging, school connectedness, social experience, and subjective well-being, sensory

Appendix 2.2: Screening full paper checklist, prior to data extraction

Inclusion criteria question **(all answers should be yes to proceed)**	**YES**	**NO**
Does the participants have autism		
Does the participants have a child/young person with autism, or support a child/young person with autism		
Does the participant (there support person) share experiential accounts of educational transitioning experiences (day-to-day or from one educational phase to another)		
Is the study a systematic review or qualitative studies, systematic review of mixed method evidence (qualitative, surveys, etc.) or a qualitative peer reviewed article.		
Exclusion criteria **(all answers should be no to proceed)**	**YES**	**NO**
Does the participant have a learning disability, intellectual disability, ‘special’ school?		
Is the data relating to kindergarten or pre-school?		
Is the data relating to transitioning into employment of vocational studies?		
Is the data un-related to educational experiences in general?		
Is the data focusing on a specific theme without relevance to the literature question (e.g., solely focused on anxiety in education without considering the larger educational context)?		
Is the data referring to specific schemes, programmes, planning, support?		
Is the data from an incomparable education system e.g., non-European (with exception of USA, Australia, New Zealand)?		

Adapted from: Aveyard et al.[227]

Appendix 2.3: JBI (2020) critical appraisal qualitative research checklist

JBI (2020) critical appraisal qualitative research checklist. Source: Joanna Briggs Institute[228] (2020)

		Yes	No	Unclear	Not applicable
1.	Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2.	Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3.	Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4.	Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5.	Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6.	Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7.	Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8.	Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9.	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10.	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion):

Appendix 2.4: Literature synthesis

Table A: Literature relating to emotional-social experiences: mental health (anxiety, fears, stress, bullying and/or discrimination, friendship, groups

Topic shared	***CTT***	**Participant sharing experience**	**References**
Emotional-social			
Sub-topic shared: ***Mental health (anxiety, fears, stress)***			
	P	***Individual with autism***	[207]
		Parent	[204, 219]
		Staff	[219]
	S	***Individual with autism***	[207, 215, 217]
		Parent	[204, 217]
		Staff	[217]
	FE/6	***Individual with autism***	[199, 201]
		Parent	[201]
	HE/Uni.	***Individual with autism***	[192, 193, 196-199, 201, 208-210, 216, 223, 225, 226]
		Parent	[201]
Sub-topic shared: ***Bullying and/or discrimination***			
	P	***Individual with autism***	[217]
		Parent	[204, 217, 219]
		Staff	[217]
	S	***Individual with autism***	[215, 217]
		Parent	[204, 217]
		Staff	[217]
	FE/6	***Individual with autism***	[208, 224]
		Parent	[224]
	HE/Uni.	***Individual with autism***	[193, 197, 208, 211, 216, 224, 226]
		Parent	[224]
Sub-topic shared: ***Friendship***			
	P	***Individual with autism***	[217]
		Parent	[202, 204, 217, 219]
		Staff	[217]
	S	***Individual with autism***	[205, 215, 217]
		Parent	[202, 204, 217]
		Staff	[217]
	FE/6	***Individual with autism***	[191, 199, 206, 208, 220, 224]
		Parent	[191, 220, 224]
		Staff	[191, 206]
	HE/Uni.	***Individual with autism***	[191-193, 197-200, 208, 209, 216, 220, 223, 224, 226]
		Parent	[191, 220]
		Staff	[191]

Sub-topic shared: ***Groups***			
	P	*Parent*	[219]
	S	***Individual with autism***	[205]
		Parent	[219].
	HE/Uni.	***Individual with autism***	[192, 193, 195, 196]

Table B: Literature related to academic experiences

Topic shared	***CTT***	**Participant sharing experience**	**References**
Academic			
	P	***Individual with autism***	[217, 222]
		Parent	[202, 204, 217, 219, 222]
		Staff	[217]
	S	***Individual with autism***	[205, 217, 222]
		Parent	[202, 204, 217, 219, 222]
		Staff	[217]
	FE/6	***Individual with autism***	[199, 200, 206, 208, 216, 220, 224]
		Parent	[220]
		Staff	[206]
	HE/Uni	***Individual with autism***	[192, 193, 196, 198-200, 208-211, 213, 216, 220, 223, 224, 226]
		Parent	[220]

Table C: Literature relating to ‘their autism’: disclosing autism and co-occurring conditions

Topic shared	***CTT***	**Participant sharing experience**	**References**
Their autism (self and others)			
	P	***Individual with autism***	[217, 222]
		Parent	[202, 204, 217, 222]
		Staff	[217]
	S	***Individual with autism***	[205, 215, 217, 222]
		Parent	[202, 204, 217, 222]
		Staff	[217]
	FE/6	***Individual with autism***	[191, 199, 200, 206, 220]
		Parent	[191, 220]
		Staff	[191, 206]
	HE/Uni.	***Individual with autism***	[191, 193, 195-199, 209, 210, 220, 226]
		Parent	[191, 220]
		Staff	[191]
Sub-topic shared: *Co-occurring conditions*			
	FE/6	***Individual with autism***	[199, 220]
		Parent	[220]
	HE/Uni.	***Individual with autism***	[192, 193, 196, 199, 216, 220]

Sub-topic shared: ***Disclosing autism and asking for support***			
	S	***Individual with autism***	[206, 215]
	FE/6	***Individual with autism***	[199, 200, 208, 223]
	HE/Uni.	***Individual with autism***	[192, 193, 196, 198, 199, 208, 223, 226]

Table D: Literature relating to the transition between CTT

Topic shared	***CTT***	**Participant sharing experience**	**References**
Transitioning between educational phases			
	P to S	***Individual with autism***	[214, 217, 222]
		Parent	[202, 204, 214, 217, 219, 221, 222]
		Staff	[203, 214, 217]
	S to FE/6	***Individual with autism***	[194, 212]
		Parent	[194, 212]
		Staff	[194, 212]
	FE/6 to HE/Uni	***Individual with autism***	[192, 193, 196, 218, 225]
		Parent	[204, 218]
		Staff	[218]

Table E: Literature relating transitioning support into and throughout an educational phase: mentoring, peer support, study skills, and support in general

Topic shared	***CTT***	**Participant sharing experience**	**References**
Transitioning support			
Sub-topic shared: ***Mentoring, peer support, study skills***			
	P	*Parent*	[204]
	S	***Individual with autism***	[205, 222]
		Parent	[204, 222]
	HE/Uni.	***Individual with autism***	[192, 193, 197, 198, 209, 210, 226]
Sub-topic shared: ***Support in general***			
	P	***Individual with autism***	[214]
		Parent	[202, 204, 214]
		Staff	[214]
	S	***Individual with autism***	[214, 222]
		Parent	[202, 204, 214, 222]
		Staff	[214]
	FE/6	***Individual with autism***	[206]
		Staff	[206]
	HE/Uni.	***Individual with autism***	[193, 197]

Table F: Literature relating to sensory experiences

Topic shared	***CTT***	**Participant sharing experience**	**References**
Sensory			
	P	***Individual with autism***	[217]
		Parent	[202, 204, 217]
		Staff	[217]
	S	***Individual with autism***	[217, 222]
		Parent	[202, 204, 217, 222]
		Staff	[217]
	FE/6	***Individual with autism***	[199]
	HE/Uni.	***Individual with autism***	[192, 193, 198, 199, 209, 210]

Table G: Literature relating to change and uncertainty

Topic shared	***CTT***	**Participant sharing experience**	**References**
Change and uncertainty			
	P	*Parent*	[204, 219]
	S	***Individual with autism***	[215]
		Parent	[219]
	FE/6	***Individual with autism***	[199, 224]
	HE/Uni	***Individual with autism***	[193, 209, 226]

Table H: Literature relating to independence experiences

Topic shared	***CTT***	**Participant sharing experience**	**References**
Independence			
	S	*Parent*	[219]
	FE/6	***Individual with autism***	[224]
		Parent	[224]
	HE/Uni.	***Individual with autism***	[194, 196, 198, 213, 216, 224, 226]
		Parent	[224]
		Staff	[194]

Table I: Literature relating to accommodation, campus, classes

Topic shared	***CTT***	**Participant sharing experience**	**References**
Accommodation-campus-classes			
	P	*Parent*	[204]
	S	*Parent*	[204]
	HE/Uni	***Individual with autism***	[193, 196, 198, 210]

Table J: Literature relating to communication

Topic shared	***CTT***	**Participant sharing experience**	**References**
Communication			
	FE/6	***Individual with autism***	[191, 199]
		Parent	[191]
		Staff	[191]
	HE/Uni.	***Individual with autism***	[191, 198, 199]
		Parent	[191]
		Staff	[191]

Appendix 3.1: Overview of preliminary study

Investigating the barriers and holistic support needs of students with ASD prior to transitioning from Further Education to University

Heather Pickard-Hengstenberg

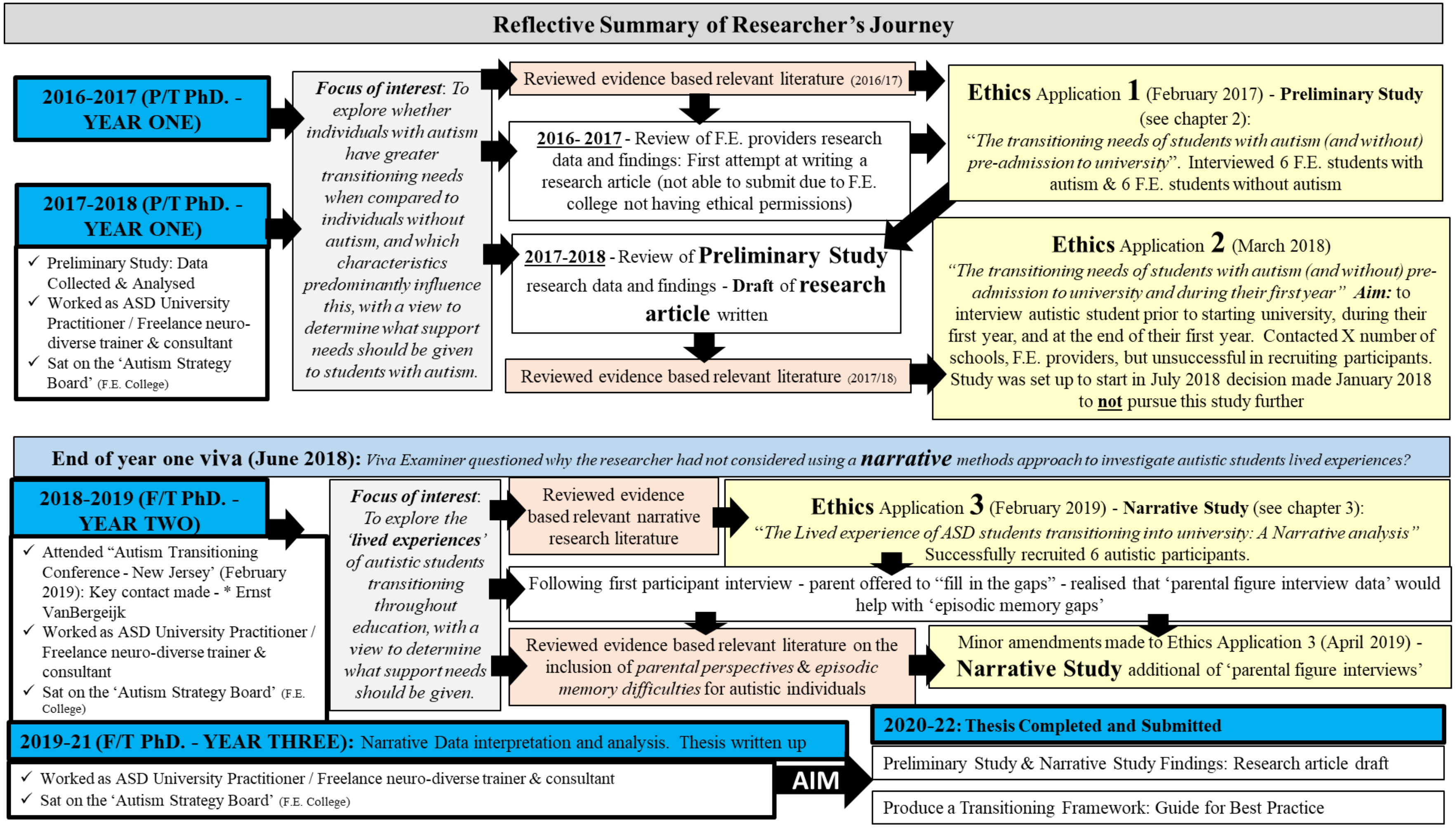
Abstract

Students with ASD have difficulties adapting to a change in their environment and/or circumstances, during transitioning, such challenges intensify feelings of anxiety and are likely to escalate into more serious mental health problems. They present a complex picture of difficulties and support needs which vary between individuals, their difficulties with self-understand impacts their ability to self-advocate to ensure they are not disadvantaged at university. The diverse needs of ASD students necessitates the involvement of a specialised multi-disciplinary team, prior to and throughout their transitioning process from further education to university, with the inclusion of skill enhancement in their FE curriculum, to ensure the most positive outcomes for them; academically, emotionally, and socially.

Conclusions

ASD students are likely to require high levels of academic, emotional, and social support during their transition into university and throughout their time there. They present a complex picture of support needs that varies between individuals and are likely to have difficulties with self-understanding and self-advocacy, necessitating a proactive support approach for all regardless of initial presentation. It is vital that F.E., H.E., ASD specialist teams, the ASD student, their parental figures, all work closely in developing a person-centred transitioning support plan that will ease the transitioning process and ensure that the ASD individual can reach their full potential academically, emotionally, and socially. In conjunction with this ASD students must be provided with plenty of opportunities to visit and ask questions, appropriate academic reasonable adjustments in place prior to starting, a specialist ASD point of contact at university that they can liaise with, and social support groups that they can attend. Institutions should ensure that all members of staff have had ASD training so that they are able to effectively use ASD communication and teaching strategies.

Appendix 3.2: Researcher's reflective summary of PhD research journey



Reflective Summary of Researcher's Journey

2016-2017 (P/T PhD. - YEAR ONE)

2017-2018 (P/T PhD. - YEAR ONE)

- ✓ Preliminary Study: Data Collected & Analysed
- ✓ Worked as ASD University Practitioner / Freelance neuro-diverse trainer & consultant
- ✓ Sat on the 'Autism Strategy Board' (F.E. College)

***Focus of interest**: To explore whether individuals with autism have greater transitioning needs when compared to individuals without autism, and which characteristics predominantly influence this, with a view to determine what support needs should be given to students with autism.*

Reviewed evidence based relevant literature (2016/17)

2016- 2017 - Review of F.E. providers research data and findings: First attempt at writing a research article (not able to submit due to F.E. college not having ethical permissions)

2017-2018 - Review of **Preliminary Study** research data and findings - **Draft** of **research article** written

Reviewed evidence based relevant literature (2017/18)

Ethics Application **1** (February 2017) - **Preliminary Study** (see chapter 2): *"The transitioning needs of students with autism (and without) pre-admission to university"*. Interviewed 6 F.E. students with autism & 6 F.E. students without autism

Ethics Application **2** (March 2018) *"The transitioning needs of students with autism (and without) pre-admission to university and during their first year"* ***Aim:*** to interview autistic student prior to starting university, during their first year, and at the end of their first year. Contacted X number of schools, F.E. providers, but unsuccessful in recruiting participants. Study was set up to start in July 2018 decision made January 2018 to **not** pursue this study further

End of year one viva (June 2018): *Viva Examiner questioned why the researcher had not considered using a* ***narrative*** *methods approach to investigate autistic students lived experiences?*

2018-2019 (F/T PhD. - YEAR TWO)

- ✓ Attended "Autism Transitioning Conference - New Jersey' (February 2019): Key contact made - * Ernst VanBergeijk
- ✓ Worked as ASD University Practitioner / Freelance neuro-diverse trainer & consultant
- ✓ Sat on the 'Autism Strategy Board' (F.E. College)

***Focus of interest**: To explore the '**lived experiences**' of autistic students transitioning throughout education, with a view to determine what support needs should be given.*

Reviewed evidence based relevant narrative research literature

Ethics Application **3** (February 2019) - **Narrative Study** (see chapter 3): *"The Lived experience of ASD students transitioning into university: A Narrative analysis"* Successfully recruited 6 autistic participants.

Following first participant interview - parent offered to "fill in the gaps" - realised that 'parental figure interview data' would help with 'episodic memory gaps'

Reviewed evidence based relevant literature on the inclusion of *parental perspectives* & *episodic memory difficulties* for autistic individuals

Minor amendments made to Ethics Application 3 (April 2019) - **Narrative Study** additional of 'parental figure interviews'

2019-21 (F/T PhD. - YEAR THREE): Narrative Data interpretation and analysis. Thesis written up

- ✓ Worked as ASD University Practitioner / Freelance neuro-diverse trainer & consultant
- ✓ Sat on the 'Autism Strategy Board' (F.E. College)

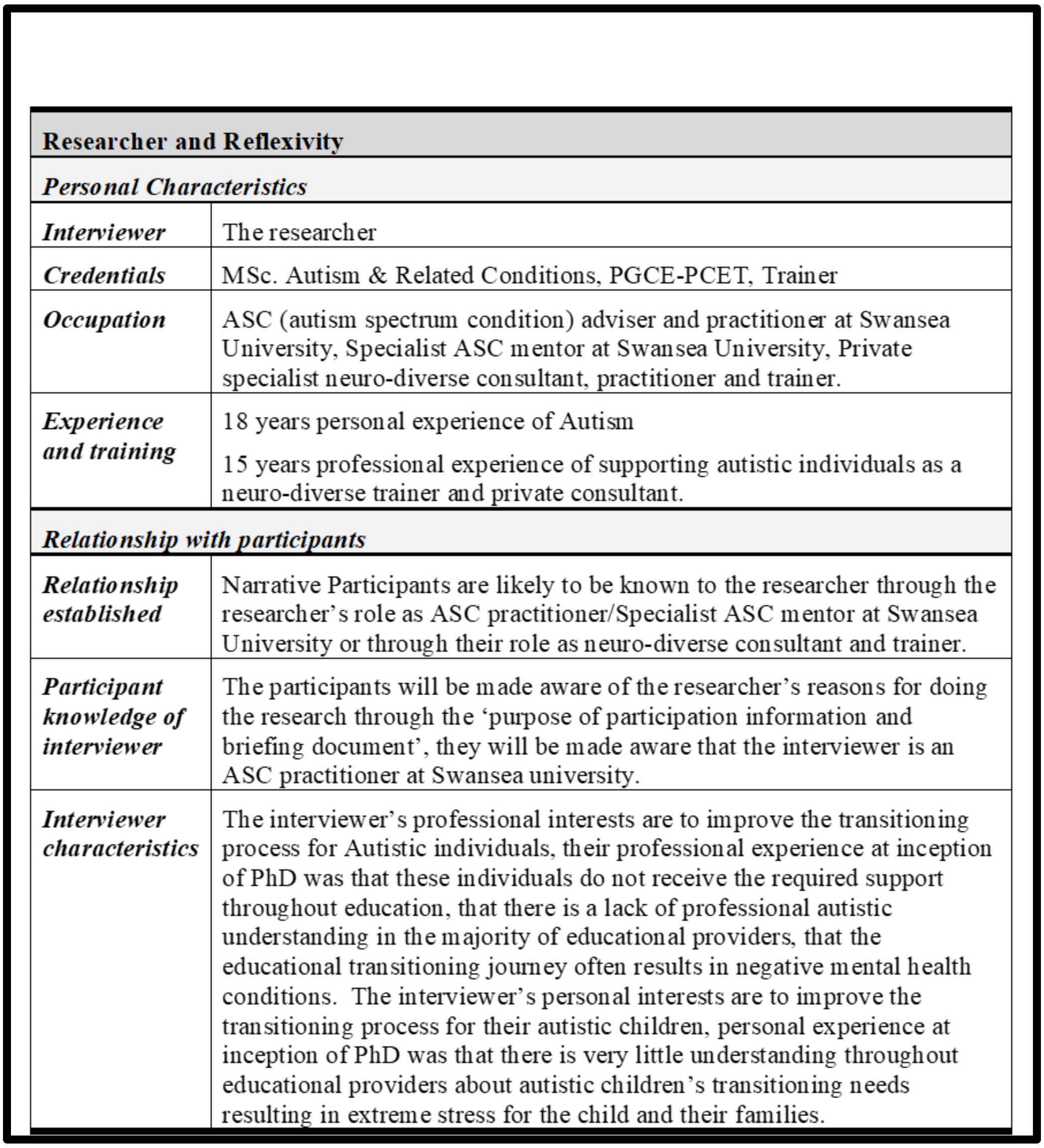
2020-22: Thesis Completed and Submitted

Preliminary Study & Narrative Study Findings: Research article draft

Produce a Transitioning Framework: Guide for Best Practice

Appendix 3.3: Researcher and Reflexivity

Researcher and Reflexivity



Researcher and Reflexivity	
Personal Characteristics	
Interviewer	The researcher
Credentials	MSc. Autism & Related Conditions, PGCE-PCET, Trainer
Occupation	ASC (autism spectrum condition) adviser and practitioner at Swansea University, Specialist ASC mentor at Swansea University, Private specialist neuro-diverse consultant, practitioner and trainer.
Experience and training	18 years personal experience of Autism 15 years professional experience of supporting autistic individuals as a neuro-diverse trainer and private consultant.
Relationship with participants	
Relationship established	Narrative Participants are likely to be known to the researcher through the researcher's role as ASC practitioner/Specialist ASC mentor at Swansea University or through their role as neuro-diverse consultant and trainer.
Participant knowledge of interviewer	The participants will be made aware of the researcher's reasons for doing the research through the 'purpose of participation information and briefing document', they will be made aware that the interviewer is an ASC practitioner at Swansea university.
Interviewer characteristics	The interviewer's professional interests are to improve the transitioning process for Autistic individuals, their professional experience at inception of PhD was that these individuals do not receive the required support throughout education, that there is a lack of professional autistic understanding in the majority of educational providers, that the educational transitioning journey often results in negative mental health conditions. The interviewer's personal interests are to improve the transitioning process for their autistic children, personal experience at inception of PhD was that there is very little understanding throughout educational providers about autistic children's transitioning needs resulting in extreme stress for the child and their families.

Adapted from: 'Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist'[305, 306]

Appendix 3.4: Researcher's reflection on their deep listening strategies implemented during narrative interview

Deep listening strategies for the researcher

Open listening strategies:

Unfocused listening

- **note**: first impressions, tone of voice, body language, intonation, social reality portrayal, character portraying themselves as, feelings triggered within them by participant)

Focused listening

- **note**: vocabulary used, signs of inner conflict, ethical considerations,
- **respect**: experiences shared and don't question validity or significance
- **reflect:** words used and/or ask for word clarification when necessary
- **ensure**: words used have been interpreted as participant intended

Meta statements: participant reflecting on their dialogue during the interview and/or their thoughts about this

- **note**: meta statements, how participant experiences them self in context of interview, how they perceive the researcher views them, signs of participants self-concept, beliefs about society, how others view (have viewed) them.
- **reflect**: meta statement back to participant, ask for more details (if appropriate), to ensure assumptions about participant's self-experiences aren't made

The logic of the narrative:

- **note**: logical sequence of participants narrative, any contradictions, reoccurring themes, how they related to one another, social context

Moral language:

- **note**: moral statements about them self or others
- **consider**: participants self-concept, social fit, 'disabled' ideologies, sense of being different, comparability to 'others'

Inner dialogues:

- **note**: when participants uses two perspectives about their experiences, if differing body language or accent are used
- consider: the influence of social pressures, family, etc., in shaping opposing perspectives

Adapted from:[351] This table was completed for every participant (parental figure)

Appendix 3.5 (a): Data collection methods - procedural steps

Data collection methods - procedural steps

(1)(a) Participant interview one

Pre-interview:
- Use ‘Narrative interview framework and prompts’ (appendix 3.10)
- Use ‘Schema notes and reflective diary entries’

During interview:
- Audio recording of interview
- Write schema notes throughout (if appropriate)

Post-interview:
- Upload audio recording of interview one to transcription service (to be returned as raw transcription data)
- Note down any additional schema notes, and reflective diary entries from the interview

(1)(b) Participant interview one - post-interview edits

- Review raw transcribed data and note this down on transcript **NB**: ensure any errors are corrected by transcription agency (i.e., when the participant’s accent or pronunciation of words is misinterpreted)
- Add schema notes and reflective diary entries to transcript where relevant
- Summarise findings for member checking

(2)(a) Participant interview two (member checking)

Pre-interview:
- Use ‘Schema notes and reflective diary entries’

During interview:
- Participant reviews summarised findings, any corrections given noted (transferred to original transcript post-interview)
- Audio recording of interview
- Write schema notes throughout (if appropriate)

Post-interview:
- Upload audio recording of interview two to transcription service (to be returned as raw transcription data)
- Note down any additional schema notes, and reflective diary entries from the interview onto interview one transcript

(2)(b) Participant interview two - post-interview edits

- Review raw transcribed data and note this down **NB**: ensure any errors are corrected by transcription agency
- Add participant corrections, schema notes and reflective diary entries to interview one transcript where relevant

(3)(a) Parental figure(s) interview (supplementary data)

Pre-interview:
- Use ‘Narrative interview framework and prompts’ (appendix 3.10)
- Use ‘Schema notes and reflective diary entries’

During interview:
- Audio recording of interview
- Write schema notes throughout (if appropriate)

Post-interview:
- Upload audio recording of parental interview(s) to transcription service (to be returned as raw transcription data)
- Note down any additional schema notes, and reflective diary entries from the parental interview and update interview on transcript where relevant to do so

(3)(b) Parental figure(s) - post-interview edits

- Review raw transcribed data and note this down **NB**: ensure any errors are corrected by transcription agency
- Add parental figure(s) **supplementary** data, schema notes and reflective diary entries to interview one transcript where relevant to the research

Adapted from:[244, 313, 314, 317, 323, 324]

Appendix 3.5 (b): Data interpretation and analysis methods - procedural steps

Data interpretation and analysis

Procedural steps - Focusing on the core of the story

Holistic-content analysis (HCA):

- Completing a chronological first draft of participant's core story by extracting; headings, core themes, life changing events, participant's perspectives about their experience, them self, their social fit
- Participant and parental quotes chosen to reflect core of the narrative told.

Categorical-content analysis (CCA):

- Breaking narrative down further into subthemes, accounting for epiphanies, plots and structural elements, characters, settings, problems arising, actions occurring, and resolutions or turning points, person and social interactions, time continuum (past present future)
- Participant and parental quotes chosen to reflect subthemes of the narrative told.

Categorical-form analysis (CFA):

- Focusing on sjuzet linguistic elements of participant's narrative using schema notes and reflective diary entries, highlighting non-verbals.
- Illustrating tonal frequencies, positive, negative, etc., related to an experience and/or TST/CTT
- Participant and parental quotes chosen to reflect tone of voice, body language, intonation, as well as the researcher's notes on meta statements when participants reflected on their self-belief, self-concept, the logic of the narrative, moral statements made, and inner dialogues observed.

Holistic-form analysis (HFA):

- Investigating how participant's spoken words form meaning in their narrative, considering the structure of narrative, how participant is positioned in it.
- Investigating participant's typology, cohesion within the narrative, turning points, narrative progression and/or regression

Critical narrative analysis (CNA):

- Investigating the functionality of the narrative to determined how the participant positioned themselves within their story, their thoughts, feelings, emotions, actions, and interactions as well as the social structure in which their stories are located, their achievements and challenges.
- Identification of a positioning theme (in conjunction with CFA data)

Theoretical models included in overall analysis:

- 'Educational transitioning model' (figure 3.6), adapted from Schlossberg (1981, 2011) 'transitioning model'[266-268], with elemental features taken from Bronfenbrenner Bio-ecological and PPCT model[255, 256]. Focusing on data relating to the participant's state of health and ability to adapt during a CTT and TST. In keeping with the research aim to identify lived experiences transitioning throughout education.
- Maslow (1943, 1987, 1993) hierarchy of needs model[257-259], to identify and demonstrate transitioning barriers experienced by a participant, factors that were preventing them from achieving their full potential, and to address the contribution that support played, lack of and/or provision of, in the success of a transition.
- Adaption of Ellaway et al[263], to explore the impact a change had on a participant within the context of their narrative, in terms of their, academic and/or emotional-social 'performance' experience, how long it took them to adapt to the change, and to address support needed.
- MacGill (2011) to consider the influence of key variables of '*potential*', '*connectedness*' and '*resilience*'[264]
- Prochaska, DiClemente and Norcross (1992) to consider the spiral movement of change as progressive stages; '*precontemplation*', '*contemplation*', '*determination*', '*action*', '*maintenance*'.[265]

Procedural steps - Completing the whole story by sequencing events chronologically
Redraft the core of the story being told: o Chronologically sequence events o Plot structural elements and code (to be able to make narrative comparisons between participants possible)

Adapted from:[244, 255-259, 263-268, 313, 314, 317, 323, 324]

Appendix 3.5 (c): The educational transitioning model analytical steps taken during each CTT

<u>This appendix illustrates the transitioning model's step wise approach that the researcher will use to analyse participant's data</u>.

Step One: Participants perception of CTT

Data will be collated on the participant's '**concurrent stressors**' (**CS**) during each ***CTT***.

1. **<u>Degree of 'CS' (linked to 'self'):</u>**

- ***'CS'/TST (dominant)***

This will include ***TST*** **CS** data, as outlined in HCA and CCA section, and '***Major CS***', dominant **CS** that has a major impact on the participant during the ***CTT*** (likely to occur across ***CTT***).

- ***'CS' (new or continuing)***

This will include any new **CS** data or continuing **CS** data from previous ***CTT***. **Ac-CS** data will only be included when there is evidence that it impacts the participant's 'state of health' and **ES** well-being.

Step Two: Participant's 'self' characteristics influencing ability to adapt to CTT

Data will be collated about the 'self' characteristics shared by the participant, and any factors which are likely to have influenced this, with the aim of providing the researcher with additional insight into the participant's narrative. Such as these preceding points (which have been discussed in depth in the literature section). For example, undiagnosed conditions, that were later diagnosed, as this may give more insight into key influential variables. For example, level of **concurrent stressor support** (CSS) provided resulting after an autism diagnosis and/or coping strategies, how the participant implemented these, and how these were used such as to; modify, take control and/or manage **CS**.

Step Three: Participant's 'CSS' and support in general influencing ability to adapt to CTT

Data will be collated on the participant's '**concurrent stressor support**' (CSS) and 'support in general', to gain greater insight into the participant's narrative and the support that was likely to have influenced their ability to adapt to the ***CTT***. This will be ranked into:

(1) Close family and friends, who provided 'stable' **CSS**. Support provided regardless of how the participant 'behaved', regarded as efficacious and resulting in positive outcomes.
(2) Support from individuals such as close teachers, 'best' friends and/or extended family members, who provided 'unstable' **CSS**. Support likely to be influenced by how the participant 'behaved', regarded as efficacious and likely to result in positive outcomes or no outcomes.
(3) Support from outside individuals, who were 'not close' to participant, who

provided 'unstable' **CSS**, influenced by how the participant 'behaved'. Support believed to not be efficacious, likely to result in negative outcomes, and increasing **CS**.

(4) No support given to participant resulting in continuation of **CSS**, negative outcomes, and increasing **CS**.

Step Four: Participant's ability to adapt to CTT

The researcher will compare the participant's preceding ***CTT*** state of health (emotional, psychological, physiological, and mental) to the current ***CTT***. Changes in the participant's state of health, **CS**, will be documented. Based on these findings the researcher will then conclude the participant's state of health that resulted from this current ***CTT*** such as:

- **Major improvement** (MaI), for example, using data to evidence that there was no mention of any 'new-continuing' **ES-CS** during this ***CTT*** such as bullying.
- **Minor improvement** (MiI), for example, using data to evidence that the participant overcame previous **ES-CS** during this ***CTT***.
- **Stable**, for example, using data to evidence that there was no mention of new **ES-CS** during this ***CTT***.
- **Minor Deterioration** (MiD), for example, using data to evidence that there was an increase in some **ES-CS** during this ***CTT*** such as social anxiety.
- **Major Deterioration** (MaD), for example, using data to evidence that there was a major increase in **ES-CS** during this ***CTT***.

Appendix 3.6: Re-storying of lived experience

<table>
<tr><td colspan="3">Re-Storying of data:
Step One – Focusing on the Core of the Story</td></tr>
<tr><td><i>Re-storying of data</i></td><td><i>One: Focus on core of story</i></td><td>Researcher combines: participant interview one and two data with parental figure data, schema notes, reflective journal entries, Sjuzet and Fabula notes.</td></tr>
<tr><td colspan="3">Data combined YES/NO</td></tr>
<tr><td colspan="3"><i>(i) Holistic-Content Analysis</i></td></tr>
<tr><td></td><td>(Holistic-content analysis)</td><td>Researcher using holistic-content analysis: completes a chronological first draft of participant’s core story creating headings (where relevant), overriding themes, life changing events as well as accounting for participant’s perspectives about their experiences, them self and their social fit. Participant quotes were chosen to reflect the core of the narrative told.</td></tr>
<tr><td colspan="3">CORE HEADINGS:</td></tr>
<tr><td colspan="3">OVERRIDING THEMES:</td></tr>
<tr><td colspan="3">LIFE CHANGING EVENTS:</td></tr>
<tr><td colspan="3">PARTICIPANT’S PERSPECTIVE ON:
• EXPERIENCES
• THEM SELF
• SOCIAL FIT</td></tr>
<tr><td colspan="3"><i>(ii) Categorical-Content Analysis</i></td></tr>
<tr><td colspan="2">Theme:
Sub-theme
• Epiphanies
• Plots
• Structural elements
• Characters
• Settings
• Problems arising
o Actions occurring
o Resolutions/Turning points
• Personal & Social interactions
• Time continuum
o Past
o Present
o Future</td><td>Notes:</td></tr>
<tr><td colspan="2">Theme:
Sub-theme
• Epiphanies
• Plots
• Structural elements
• Characters
• Settings
• Problems arising
o Actions occurring
o Resolutions/Turning points
• Personal & Social interactions</td><td>Notes:</td></tr>
</table>

• Time continuum o Past o Present o Future		
Theme: Sub-theme • Epiphanies • Plots • Structural elements • Characters • Settings • Problems arising o Actions occurring o Resolutions/Turning points • Personal & Social interactions • Time continuum o Past o Present o Future		Notes:
(iii) Holistic-Form Analysis		
	(Holistic-form)	The researcher uses holistic-form analysis, noting how the story is joined together, linked, through spoken language to form a meaning.
How is the story joined together? Linkage – spoken language forming meaning…		
(iv) Categorical-Form Analysis		
	(Categorical-form)	The researcher focuses their analysis on the sjuzet, the ways in which the participant tells their story, utilizing the information gathered from; reflective diary entries made reflecting on the deep listening strategy outcomes, to highlight non-verbal communication, researcher reflexivity. The researcher adds direct quotes to each heading to support findings.
REFLECTIVE DIARY (DEEP LISTENING STRATEGIES): (highlight non-verbal communication, researcher reflexivity, Sjuzet and Fabula) • Sjuzet, the plot in which the narrative is told, how the participant tells their story, intonation, tone of voice, over emphasising, and so on, **Open Listening** *Unfocused*; Researcher is mindful of first impressions, factors that appear such as; tone of voice, body language, intonation, social reality being portrayed, character that they are portraying them self as (victim, hero, etc.). The feelings triggered within the researcher resulting from listening to the experiences shared are noted. *Focused Awareness*: Researcher focuses on the participant's vocabulary, reflecting back and/or asking for word clarification when necessary. Ensuring that words used by the participant have the interpreted meaning that the participant intended. Researcher; looks for signs of inner conflict, is mindful of ethical considerations throughout, respectful of the experiences shared without questioning their validity or significance **Meta Statements** When the participant reflects on their own dialogue used in the interview and/or thoughts about this. The researcher pays attention to these, noting their occurrence as they reflect how the participant is experiencing them self in the context of the interview, with the potential to demonstrate to the researcher their perception of how the researcher (others) view them. When a		

participant uses a meta statement the researcher, through reflective questioning, will ask for more details (if appropriate to do so) to ensure that the researcher does not make Assumptions about the participants self-experiences. The researcher focuses on signs of participants self-concept, their beliefs about how society, other individuals, view (have viewed) them.		
The logic of the narrative The researcher pays attention to the logical sequence of the narrative; any contradictions that occurs, reoccurring themes and how they relate to one another, their social context.		
Moral Language Participant language that passes moral statements about them self or others will be noted by the researcher, this enables the researcher to consider the participants self-concept, social-fit, disabled ideologies, their sense of being different, and how the participant evaluates them self to a comparable,		
Inner Dialogues When the participant uses two perspectives to talk about their experiences, one may be positive and reassuring and the other negative and self-critical, the researcher considers the influence of social pressures, family pressures, etc., in shaping these opposing perspectives. NB: If an alternative accent/voice is used this will be noted.		
(v) Critical Narrative Analysis		
	(Critical narrative analysis)	The researcher considers the positioning of the participant, within their story, their; thoughts, feelings, emotions, actions, and interactions as well as the social structures in which their stories are located, their achievements and challenges.
Positioning of Participant within their story • Thoughts • Feelings • Emotions • Actions • Interactions • Social structure (in which story is located) • Achievements • Challenges		
Redraft of core of story		
		Researcher redrafts the core of the story being told
Completion of story: sequencing events chronologically		
	Two: Complete the whole story by sequencing events chronologically	• Chronologically sequencing events • Plot structural elements and code (to make story comparisons between participants possible)
Codes used to plot structural elements:		

Appendix 3.7: Ethical consideration

This appendix contains detailed information about the ethical consideration, regarding: Issues pertaining to human subjects. Purpose of participation, briefing, reciprocity and promises. Potential risks. Confidentiality and anonymity. Informed Consent. Debriefing, mental health procedures and ethical advice. Reported findings, access, and ownership. Data storage and Disposal. Patton[254] checklist of common ethical issues was implemented prior to writing the ethics applications and the researcher was mindful of these points throughout the narrative study, as outlined below:

> "*1. Explaining purpose. 2. Reciprocity. 3. Promises. 4. Risk assessment. 5. Confidentiality. 6. Informed consent. 7. Data access and ownership. 8. Interviewer mental health. 9. Ethical advice. 10. Data collection boundaries. 11. Intersection of ethical and methodological choices. 12. Ethical versus legal*".[352(p496-497)]

In the context of this research, it was essential that the researcher considered their relationship with the participant in terms of ethics. Josselson (2007) described the ethical difficulties facing narrative researchers when it came to their relationship with the participant:

> "*the ethical conundrum in narrative research derives from the fact that the narrative researcher is in a dual role – in an intimate relationship with the participant (normally initiated by the researcher) and in a professionally responsible role in the scholarly community. Interpersonal ethics demand responsibility to the dignity, privacy, and well-being of those who are studied, and these often conflict with the scholarly obligation to accuracy, authenticity, and interpretation*"[304(p538)].

The researcher prepares for and will include Josselson[304] two types of contracts, between them and the participant: First, the explicit contract, outlined in the research's ethics application, and the purpose of participation, briefing and consent documents. Second, the implicit contract, which could not be easily documented in the ethics application prior to the interview as it is based on the relationship that occurs during the interview between the researcher-participant. The researcher has implicitly aimed to; connect, positively communicate, empathise, respect, respond appropriately, build trust and rapport with the participant,[304] which will be demonstrated in the schema notes and reflective diary entries.

Ethics: Issues pertaining to human subjects

Interviewing autistic participants, potentially vulnerable and/or traumatized by their educational experiences, required the researcher to seriously think about the purpose of their interview and the effect that this might have on the participant. Clarity about their role as the interviewer was necessary first and foremost, that this role was to gather important data for the research study, that it should not be a therapeutic appointment, however the interview had the potential to trigger strong emotions that would require empathetic support that the researcher was equipped to provide. Participants were also provided with information about groups whom they could seek advice or help from if the interview invoked the need for it. Providing follow up narrative interviews not only allowed for member checking but also provided participants with the opportunity to discuss any points raised that they needed to address. The provision of a research email contact address gave participants a platform to communicate with the researcher, with any research related questions, if they needed too. Interviewing parental figures during the narrative study required the same level of consideration given to the participants. Oversharing of confidential information not relevant to the research question was an ethical issue that the researcher anticipated prior to interview, and their professional experience working with individuals, their parents, enabled them to guide the flow of conversation to a more relevant area, if they needed to.

Ethics: Purpose of participation, Briefing, Reciprocity and Promises

Ethically participants explicated were told that by partaking in the study that the research aimed to benefit the autistic individual transitioning throughout education through publications, the creation of a

‘Transitioning guide for best practice framework’ for educational providers, with the intention to empower such individuals. All narrative research participants (their parental figures) were informed about the purpose of their participation in the study through a briefing sheet and purpose of participation sheet, prior to their agreement to partake in the study. These briefing and purpose of participation documents detailed the purpose of the research, the procedures involved, supervisor contact details, and they were reviewed again in person (or over the telephone in some cases with parental figures) prior to the interview starting. The purpose of participation sheet clearly outlined to the participant why they were being asked to take part in the research study. Due to the extensive time requirements of the narrative study participants were reciprocated through the provision of refreshments and a voucher, following completion of the interview, as a thank you for their contribution. Following on from all research study interviews participants were debriefed and, on this document, asked if they would like a copy of the summary of findings, a record was made of this request and the promise of this adhered to.

Ethics: Potential risks

In the narrative study the potential risks to participants, their parental figures, considered prior to commencement of the research study were anxiety and/or stress responses resulting from talking about their educational experiences. The researcher’s professional role as an autism practitioner, Neuro-diverse consultant, and trainer, equipped them to manage such situations should they arise by implementing appropriate measures such as; de-escalation, stress reduction strategies, redirection, and so on. During the ethics applications, within the briefing documentation and throughout the narrative study the researcher emphasised that if at any point they or any individual present felt that the interview was causing unnecessary stress to the participant, their parental figure, then they would stop the interview immediately and address the stress trigger if appropriate to do so. The researcher also ensured that the participant, their parental figure, was aware of appropriate support persons or services available to them. The researcher was mindful throughout the narrative study, about their relationship with the participant, their parental figure, to ameliorate the potential of inappropriate relations between them self and the participant, their parental figure, the researcher ensured that they had no personal relationship with any participant in this study, keeping all conversations related to the research topic. All correspondence via the research email address made clear in its email signature, as well as briefing documents, that this email was for the purposes of the research study only and that any unrelated matters should go through another more appropriate address e.g., if the student had questions related to support with their studies then this should go through the autism service. No personal identification information from the researcher was shared with the participant or their parental figure. Throughout the research process, during the briefing, on the consent form and during the interview, the participant (parental figure) was made aware of their right to withdraw from the research at any point without any penalty incurred. They were also given the contact details of the researcher’s supervisors should they wish to discuss the research or make a complaint.

Ethics: Confidentiality and anonymity

An anonymous system of unique coding was used to label and identify participant data which was only known by the researcher and their supervisor. In the write up of individual participant data each participant was given a pseudo name to protect their anonymity. All documentation was stored in accordance with data storage procedures and in agreement with the requirements set by the ethics committee.

Ethics: Informed Consent

Informed consent and data storage adhered to ethical requirements and data protection laws. Data representation accounted for and adhered to ethical considerations in the context of; the role of the researcher as a collaborator, interpreter and reporter of findings, access, and ownership. Ethical practice was adhered to through participant documents which detailed; purpose of participation, briefing, debriefing, reciprocity and promises adhered to. Ethical issues pertaining to human subjects were accounted for, and potential risks minimised. Participants considered to be ‘vulnerable’ lacking the capacity to make specific important decisions under the Mental Capacity Act (2005) over the age of 18 years needed informed consent from their parent (legal guardian or legal advocate).[353] A signature from all participants, regardless of age and/or mental capacity, was also obtained to demonstrate that they wanted to partake. Participants (parental figures) over the age of 18 years were asked to give their consent to partake. Before the research interviews informed consent was verified by the researcher and participant (parental figure). As part of the ethics application, it was made clear by the researcher to every participant that if at any point during the interview they had any doubts about participants’ abilities to give informed consent, that the participant did not wish to participate, then the researcher would stop the interview immediately. Participant (parental figure) consent documentation was stored electronically in a secure data base in accordance with data storage procedures. Another ethical consideration in terms of informed consent was that even though participants were aware that they could withdraw at any time throughout the study, the researcher still needed to be mindful of any signs of ‘subtle coercion’, being pressurized to partake unwillingly, to ensure that this was not the case, that they were not suffering any undue pressure or stress, the researcher reminded participants regularly that they could withdraw at any time.

Ethics: Debriefing, mental health procedures and ethical advice

At the end of the interview the participant (parental figure) was given a debriefing sheet, on which they confirmed that they had been given; the opportunity to ask the researcher any related questions. On the briefing sheet they confirmed that they had received a briefing and debriefing, as well as indicating on this sheet whether they would like to receive a summary of findings upon completion of the research study. The researcher was given the opportunity to debrief and discuss any issues or concerns related to the participant (parental figure) interviews with their supervisor during their monthly supervision session, however if supervisory support was needed sooner than this could be arranged via email. The researcher sought ethical advice throughout from their supervisory team as well as the ethics committee at Swansea University.

Ethics: Reported findings, access, and ownership

Relating participant data into a theoretical context involved interpretation by the researcher in terms of its narrative data, comparability between cases, and theoretical nature in terms of literature. There were ethical concerns that had to be considered, such as how the narrative participant might feel when they read the report findings, especially as the inclusion of direct quotes meant that they would be able to easily identify them self. The researcher had to be mindful of the fact that some participants might not fully agree with the portrayal of their experiences, when the researcher included an account of their non-verbals, which they might not be aware of. The research also considered how, even with anonymity, participants from small communities, might easily recognise each other in the text. Whereas other participants may see their contribution to the report findings as a portrayal of their experiences and they may view it as a cathartic opportunity to express these to the wider world. The researcher was aware that participant responses could not be anticipated ethically. To manage the concerned previously addressed, they ensured that they were respectful, tender, and honest, in their portrayal of the participant’s voice, when writing the reported findings. They also ensured anonymity, confidentiality and data protection laws were adhered to, data access and ownership of data was explained to the participant(s) in the consent forms given.

Ethics: Data storage and Disposal

Hard copies of all participants, parental figure, data were stored in a locked filing cabinet in a locked room accessible only by the researcher’s primary supervisor. Soft copies of research data, such as interview audio recordings, interview transcripts, participant email correspondence documents, were stored on a secure and password protected university computer system, with participants identifiable via a unique coding system and encrypted with a password. Recordings made during the interviews on the audio device were; securely downloaded on a secure computer system immediately after the interview, uploaded to the transcription service used and then deleted from the audio recording device. Storage and disposal of data was in accordance with the Data Protection Act 2008 and the General Data Protection Regulation (GDPR) 25th May 2018. Participants and parental figures were informed of data storage and disposal during initial correspondence, briefing documents, and in the signature section of all email correspondence. They had the right to withdraw from the study at any point and could request that all personal data be destroyed if they so wished. Upon completion of the research participants who requested a summary of findings were to be emailed this and then four weeks after the final email is sent all email correspondence, and the email account set up for the research, would be deleted. The email account set up for the research is a secure account and password protected. In the unlikely event that the researcher's university system lost data, the research data was backed up electronically by the researcher every 4 weeks and given to their primary supervisor during their supervision sessions on a password protected USB drive which was stored in the supervisor's locked filing cabinet, in their locked office, accessible only by them. Upon completion of the research USB drives will be deleted by the supervisor in accordance with the disposal of data timelines outlined in the ethics applications.

Appendix 3.8: Quality Criterion

This appendix outlines the research quality assurance, its: Credibility, Confirmability, Dependability, Transferability, and Plausibility.

Researchers argue that the application of internal validity criteria used in qualitative research, which requires **assessing** outcomes of participants as a whole, goes against research's naturalistic axiom that individuals' realities (their experiences) are multiple in nature, unique from each other and must be interpreted within their contexts not as a whole.[251] This research focuses on individual's lived experiences through a naturalistic approach, findings will not be generalisable[231] or replicable[251] and the researcher will be part of the research,[231] thus not meeting the quantitative criteria for external validity. A more feasible equidistant criteria, has been used in this research, which addresses the quality and trustworthiness of this naturalistic study, designed by Lincoln et al[250] which enables the assessment of the research's quality in terms of its; credibility, confirmability, dependability and transferability.[250, 251, 354] These points are also supported by Polkinghorne (2007) with additional elements of plausibility and trustworthiness added.[355]

In addition to the points raised above, the researcher recognises the importance of being immersed in the field under investigation, as is the case within this study as the researcher is professionally and personally involved in supporting individuals with autism transitioning. Armstrong[356] raised the important point of a fair return, that the participant gets some value from the time that they spend partaking in the research. In this narrative research study participants will receive confections during their interviews and a voucher after the interview as a way of thanking them for their time. They will also be reminded about the importance and value of their stories within the world of autism and how these stories have the potential to one day help someone like themselves to have a more positive transitioning experience.

The quality of this narrative research will be demonstrated through detailed description of its; credibility, confirmability, dependability, transferability and plausibility , and detailed researcher reflexivity throughout. 'Deweyan' theoretical belief inspires the researcher's aim to positively influence other researchers' perspectives about individuals with autism through this research.

Credibility

To ensure credibility of the research and to counterbalance any potential for researcher bias the researcher, prior to starting the study, has done a thorough evidence-based literature search in this area, identifying that transitioning difficulties do not just occur for individuals with autism in the UK but throughout the world as outlined in the literature review chapter. Evidencing the credibility of this research, whether it is a reliable source of information about the experiences of individuals, will be demonstrated through: (1) Detailed schema notes (Sjuzet and Fabula) and reflective diary entries, which will be written during and directly following every interview. (2) The utilisation of a university approved independent transcription service for transcription of all audio data. (3) The researcher verifying and checking all transcription materials received to ensure accuracy. (4) Member checking by participants of researcher's detailed notes about their first transcribed interview, checking direct quotes, intended meanings, and any further clarification needed. (5) Using direct quotes from participants in conjunction with the researcher's schema notes and reflective diary entries, to ensure that the naturalistic and contextual elements are fully reported. (6) The inclusion of parental figures to support data given by participants with episodic memory difficulties. (7) Inductive data analysis to identify patterns and themes. (8) Regular peer debriefing throughout all aspects of the research study. (9) The researcher's supervisory team randomly selecting participant data to verify, and check analysis implemented. (10) In addition to these points the credibility of this research will be demonstrated further by the researcher's inputting their specialist knowledge and understanding in this specific field as a result of their personal and professional background and experiences.[250] Appendix 3.3, supports the researcher's credibility, by reflecting on their; identity, experiences, occupation and qualifications, so that all readers can assess these factors and how they may impacts the researcher's interactions as well as decision making and interpretations of data.[305, 357]

The final transcripts

These have been made available to academic readers and/or auditors upon completion of the research study, they are not be intended to be read in isolation as factual representations of lived experiences but as part of the narrative reported findings, whereby the reader must consider them in the context of the complete narrative interpretive study, taking account of the research's methodology used, the re-storied portrayal of 'experiences', and in the context of relevant current evidence-based literature.

Confirmability

The research steps that will be taken throughout the narrative research study, from its initial proposed hypothesis to its reported findings, aim to be confirmable by other researchers in the field as being credible data due to their transparent audit trail which will be presented throughout this thesis. Auditors will be presented with evidence demonstrating that the reported findings have been thoroughly grounded in research data, not interpreted by the researcher based on their subjective preferences or viewpoint, substantiated further by the researchers schema notes and reflective diary entries, their methodological reasoning behind their decision to use a NA approach in their data analysis, reporting of findings, data management, as well as their detailed critical reflection.[358] The points illustrate the basis for the researcher's decisions and reasoning throughout the research processes.

Dependability

To be able to establish whether the research findings are dependable the researcher will evaluate the processes used throughout in terms of; data collection, analysis and reported findings. The points discussed in the context of credibility demonstrate elements of quality, however, the researcher is aware that some researchers may argue that due to the naturalistic nature of the research study that it may not have been possible for the researcher to be truly objective and not be swayed by their viewpoint.[251] As discussed in the context of confirmability and plausibility , the audit trail presented in this chapter, and detailed narrative coherent methods employed, as outlined in the next section, aim to support the researchers overall dependability when being evaluated.[250]

Transferability

Transferability of this research is dependent on whether its reported findings could be applied to other individuals (with autism) transitioning throughout education.[359] McInnes et al[251] points out that it isn't the responsibility of this researcher to ensure that the findings are transferable, their aim is to ensure that the findings are presented in a format that is holistic and full of detailed descriptive information which would enable other researchers to make the decision whether this research is transferable or not to their research study based in a similar setting.[355, 359] Detailed descriptions about participant selection and recruitment, as well as methods used, in this research have been provided by the researcher as an attempt to further assist other researchers decisions about this research's transferability.[318]

Plausibility

Defining plausibility of narratives was debated by Rideout[360] who emphasised that for a narrative to be plausible it needed to have narrative coherence, which would be broken down into external coherence and internal coherence. External coherence criteria will be met throughout this research when narratives are compared with similar narrative in evidence-based literature, as reflected in the literature review chapter and in the context of the discussion chapter. Internal coherence of participant's narratives, whereby the parts of the narrative form a logical sequence creating ‘the story’, will be demonstrated in this research, both through its data analysis and re-storying of participant data. The inclusion of theoretical frameworks as a guide during data analysis, re-storying, aim to support justification for the sequential representation of each individual participant’s story, illustrating internal coherence and overall plausibility . The ultimate demonstration of plausibility throughout this research will be the presentation of a participant narrative data that allows the reader to ‘make sense’ of the individual with autism unique transitioning experiences, their reality, from their point of view, within the context of their coherent narrative.

Appendix 3.9: Test interview assessment guide

Adapted from NICE public health guidance[361] (2012) 'Methods for the development of NICE public health guidance (third edition) Process and methods'

Conclusion following test interview

- Ensure that the participant clearly defines each educational phase, the name of education phase and the age attended (they often cross over, and points are raised in the context of another phase resulting in potential confusion).
- The interviewer must be mindful not to lead the narrator, allowing their story to flow naturally wherever possible. Using prompts to guide when the participant relays information that is not relevant to the research questions (although being mindful of allowing a story to run its course, particularly if it has emotional significance).
- The interviewer needs to use questions/prompts in a more relaxed manner to allow a natural narrative flow without interrupting the participant, unless it is key, to avoid a sense of "next question"

Research aim:	To enable individuals with autism to share their perspectives on their lived experiences, to use participant's life stories as a platform to understand their world and the wider world from which they come, to influence policy makers implementation of strategies that will reduce existing disabling barriers
Theoretical approach	
1. Did the primary related questions/prompts result in data relevant to transitioning experiences? ***Comments:*** YES - however some confusion between educational phases - need to ensure that the participant clarifies each education stage with age attended. e.g., Primary for pilot participant consisted on 2 educational establishments. If they are separate, then need to be discussed separately e.g., infant, and then junior.	
• Academic related: YES • Emotional related: YES • Social related: YES • Physical/Sensory related: YES • Transitioning between educational phases related: YES	
2. Did the secondary related questions/prompts result in data relevant to transitioning experiences? ***Comments:*** YES - Recalling bullying during educational phase may trigger upset that interviewer must be empathetic with and given the participant sufficient time to share, even information that is not relevant to the research questions, as it is still an important part of their narrative that they are openly processing.	
• Academic related: YES • Emotional related: YES • Social related: YES • Physical/Sensory related: YES • Transitioning between educational phases related: YES	
3. Did the sixth form related questions/prompts result in data relevant to transitioning experiences? ***Comments:*** YES - need to ensure clarity of terms "sixth form" / "college"	
• Academic related: YES • Emotional related: YES • Social related: YES • Physical/Sensory related: YES • Transitioning between educational phases related: YES	
4. Did the university related questions/prompts result in data relevant to transitioning experiences? ***Comments:*** YES - need to ensure clarity of education phase if the participant attended an undergraduate course and then a post graduate course. These must be separated and addressed as individual transitioning phases.	

- Academic related: YES
- Emotional related: YES
- Social related: YES
- Physical/Sensory related: YES
- Transitioning between educational phases related: YES

Based on the interview questions/prompts is the study clear in what it seeks to find out?

Comment: YES - although the interviewer must be mindful not to lead the narrator - allowing their story to flow naturally wherever possible. Using prompts to guide when the participant is not relaying information that is not relevant to the research questions (although being mindful of allowing a story to run its course, particularly if it has emotional significance).

Study design

1. Are the questions/prompts appropriate? YES
2. ***Anything missing?*** NO - although it is necessary to use questions/prompts in a more relaxed manner to allow a natural narrative flow without too many interruptions from the interview, or a sense of "next question" …
3. Anything that needs to be removed? NO

Does the data collected from questions/prompts allow for:

1. ***Holistic-content analysis***? YES - clearly defined identifiable 'core transitioning themes (phases)' were easily identifiable' - Although - must ensure that the participant clarifies each individual educational phase and age attended.
2. ***Categorical-content analysis***? YES - clearly defined identifiable 'transitioning sub-themes'. That could be easily categorized into **concurrent stressors** (**CS**). Data can easily be used within the context of the 'transitioning framework' to identify state of health prior to and during the transition in order to assess participant's ability to adapt to transitioning phase.
3. ***Holistic-form analysis***? YES - data (in particular the reflective diary entries, fabular and sjuzet notes) allowed for researcher to analyse progressive/regressive features of the core narrative and also the sub-themes. As well as typology.
4. ***Categorical-form analysis***? YES - data (in particular the reflective diary entries, fabular and sjuzet notes) allowed for researcher to analyse linguistic properties (verbals/nonverbals)
5. ***Critical narrative analysis***? YES - all the detailed data and researcher notes taken during the test interview enabled the researcher to identify functionality of the narrative and typology.

Trustworthiness

1. ***Role of the researcher during the test interview?*** - Rapport appeared to be easily established between participant and researcher and the conversation flowed in a relaxed manner. Role very much is one of collaborator, encouraging the narrative to flow and be unsolicited.
2. ***Did the participant understand the context of questioning/prompts***? YES - most of the time. Researcher/interviewer must ensure that the flow of prompts/questions is as naturalistic as possible. At times, the interview sounds like "next question" - this must be avoided.
3. Is the transcribed data rich in detail relevant to the research question? YES and the detailed reflective diary entries further enrich this.

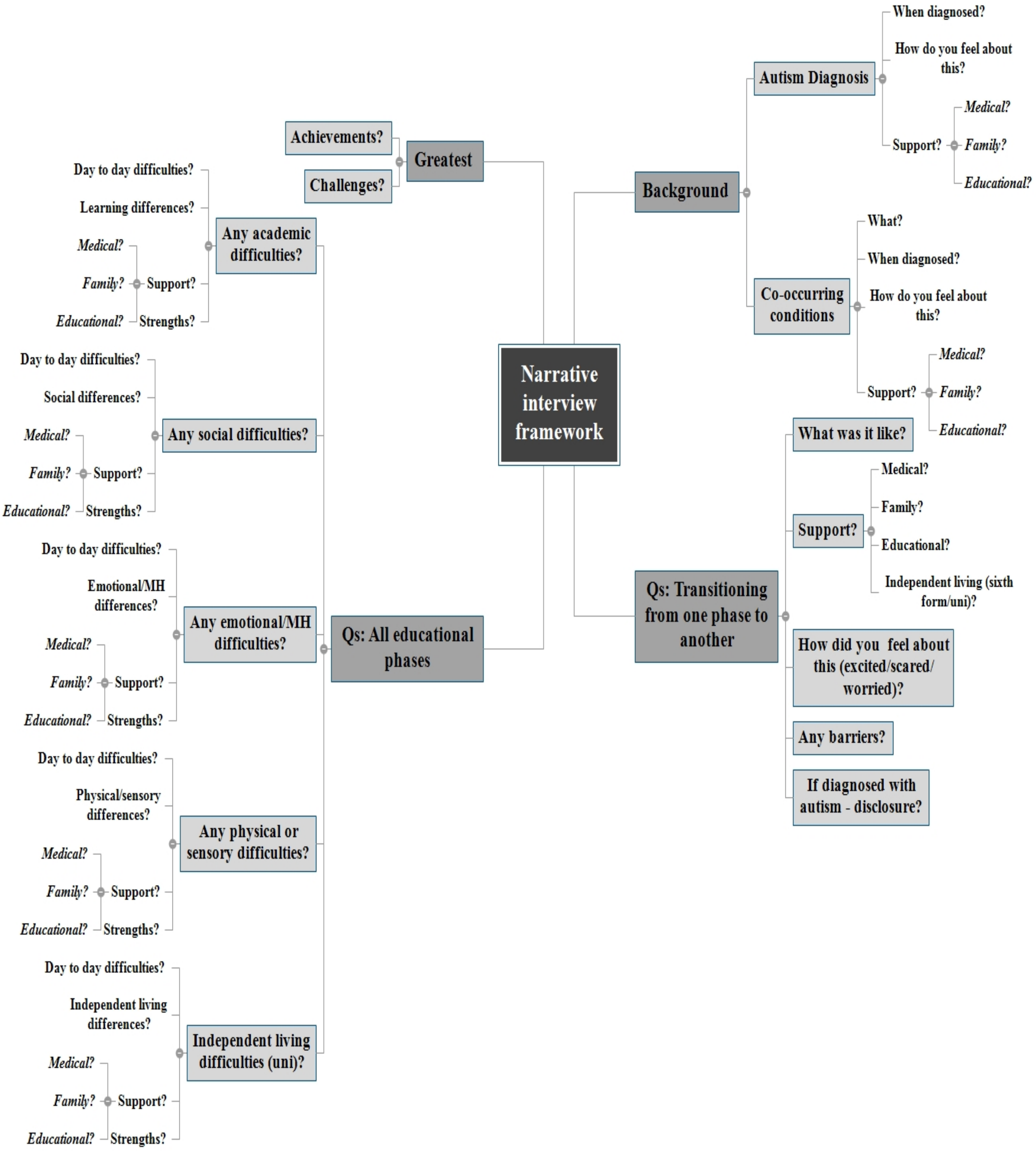
Ethics

1. Did any ethical considerations arise from the interview? NO

Overall outcome/assessment of the test interview

- Ensure that the participant clearly defines each educational phase, the name of education phase and the age attended (they often cross over, and points are raised in the context of another phase resulting in potential confusion)
- The interviewer must be mindful not to lead the narrator - allowing their story to flow naturally wherever possible. Using prompts to guide when the participant is not relaying information that is not relevant to the research questions (although being mindful of allowing a story to run its course, particularly if it has emotional significance).
- The interviewer needs to use questions/prompts in a more relaxed manner to allow a natural narrative flow without interrupting the participant, unless it is key, to avoid a sense of "next question" …

Appendix 3.10: Narrative interview framework and prompts



Appendix 3.11: Data coding criteria for participants and their parental figure

Summary of data coding criteria for participants and their parental figure

Participant and parental figure(s) data coding criteria	
Description	**Example of coding**
Participant identifiable code	**P201**
Interview one	no code given
Interview two	**int.2**
Time point in interview (hour.minute.second)	**01.02**
Parental figure	**PF**
Parental figure mum	**PFM**
Parental figure dad	**PFD**
"Fabula quote" $^{\text{plus associated coding}}$	"***it was hell***" $^{\text{P201/01}\cdot\text{02}}$
"Fabula quote" **(Sjuzet data)** $^{\text{plus associated coding}}$	"*it was hell*" **(sad tone, withdrawing into self)** $^{\text{P201/01}\cdot\text{02}}$

Appendix 4.1 (a): Categorical-Form Results (Mark): Detailed linguistic dialogue data, tones, non-verbals, and frequency of use

Table A: Summary of complete linguistic dialogue used by Mark during interview one and interview two, in the context of themes, sub-themes, and concurrent stressors

	Tones and/or Non-verbals	**Frequency**
Dominant Primary Tone: Positive	**relaxed f=45** **happy f=18** **excited f=5** **smiling f=2** **upbeat f=2** **laughing f=1**	**f=73**
Dominant Secondary Tone: Factual	**Factual**	**f=68**
‘Other’	Expressive f=16 Hesitant f=9 Confused f=3 Neutral f=1	f=29
Serious	Serious	f=27
Negative	Withdrawing f=15 Despondent f=7 Worried f=1	f=23

Table B: Positive (relaxed & or happy) Linguistic dialogue used by Mark, during interview one and two, in the context of themes and sub-themes (concurrent stressors)

Discussing autism	***f=15***
• *Being undiagnosed ASC*	*f=4*
• *Secondary school teachers not being aware he had **autism***	*f=2*
• *SIXTH FORM - Worried about people judging him because of his **autism** (diagnosed sixth form 2nd year)*	*f=1*
• *SIXTH FORM - **autism** DIAGNOSIS - no more unsureness*	*f=1*
• *SIXTH FORM - describing when he got his diagnosis*	*f=4*
• *UNI - disclosing **autism** - bit of apprehension*	*f=2*
• *UNI - disclosing **autism** to peers*	*f=1*
1st & 2nd Primary School - Mark described	***f=8***
Academic	***f=6***
• *ACADEMIC - discussing academic struggles - English/math*	*f=2*
• *ACADEMIC - discussing academic struggles - being forced to spontaneously do creative writing*	*f=2*
• *C.S.S. - may have been teaching* assistants	*f=1*
• *Handwriting - illegible*	*f=1*
Emotional-social	***f=2***
• *EMOTIONAL-SOCIAL - didn't have friends or anyone to confide in*	f=1
• *SOCIAL - aspects of beavers and cubs found difficult*	f=1
Secondary School -Mark described	***f=18***
TRANSITIONING	***f=5***
• *Memories of open day and visit to school*	f=2
• *Transition event prior to starting - met friend*	f=1
• *Transition event prior to starting - asked to do icebreaker*	f=1
• *Recalling first day of school - being dropped off by mum*	f=1
Academic	***f=4***
• *ACADEMIC - in lower sets - private tutor*	f=1
• *ACADEMIC - struggling with creative writing*	f=1

• *ACADEMIC - extremely slow handwriting due to perfectionism*	f=1
• *ACADEMIC - reasonable adjustments*	f=1
Emotional-Social	***f=9***
• *SOCIAL - aspects of beavers and cubs found difficult*	(above)
• *SOCIAL - discussing social aspects - mafia mentality of peers*	f=2
• *SOCIAL - discussing two friendship groups*	f=1
• *SOCIAL - discussing best friend*	f=2
• *EMOTIONAL - discussing people making fun of him*	f=2
• *EMOTIONAL - becoming more emotional internally with own dialogue - not yet expressing this to others*	f=2
Sixth Form - Mark described	***f=6***
TRANSITIONING	***f=1***
• *Interview for sixth form*	*f=1*
Academic	***f=1***
• *ACADEMIC - enjoyment of history*	*f=1*
Emotional-Social	***f=4***
• *SOCIALISING - wasn't difficult for him*	*f=2*
• *SOCIAL - would get a buzz from socialising with peers*	*f=2*
University - Mark described	***f=26***
TRANSITIONING	***f=9***
• *TRANSITION SIXTH FORM TO UNI - fine with self-independence skills*	f=1
• *SIXTH FORM COLLEGE PREP FOR UNI - general admin*	f=1
• *VISITS TO THE UNI - describing first time visiting his uni*	*f=1*
• *REASON FOR CHOOSING UNI -*	*f=2*
• *2nd VISIT TO CHOSEN UNI - meeting autism team*	*f=1*
• *Uni transition support given*	*f=1*
• *Decision to go to uni*	*f=1*
• *Discussing prep for uni*	*f=1*
Academic	***f=5***
• *ACADEMIC - what most excited about - studying Napoleonic major*	*f=1*
• *ACADEMIC - found it easier at uni - less fact-based - more argumentative style*	f=1
• *ACADEMIC CHALLENGE - self-discipline*	f=1
• *ACADEMIC - discussing specialist tutor support*	f=1
• *ACADEMIC support*	f=1
Emotional-Social	***f=9***
• *SOCIAL - what most excited about - meeting new people*	*f=1*
• *EMOTIONAL - How much he changed at uni*	*f=1*
• *SOCIAL - not many issues - didn't interact with peers who were drunk*	*f=1*
• *EMOTIONAL-SOCIAL - discussing specialist mentor support*	*f=2*
• *SOCIAL - most excited about 1st term*	*f=1*
• *EMOTONALLY - now totally opposite - expressive*	f=1
• *EMOTIONALLY - greatest challenging transitioning in uni - being emotionally callous before*	f=1
• *EMOTIONALLY - greatest achievement*	f=1
'C.S.S.'	***f=3***
• *UNI SUPPORT - aware of some - knew more talking to* ***autism*** *practitioner in first term*	f=1
• *'C.S.S.' UNI - wellbeing/dsa/study skills tutor/mentor*	f=1
• *UNI support first term*	f=1

TOTAL	***f=73***

Table C: Negative Linguistic dialogue used by Mark, during interview one and two, in the context of themes and sub-themes (concurrent stressors)

Discussing autism	***Withdrawing*** ***f=1***	***Despondent***	***Worried***
• *Secondary school - getting parents to accept **autism** and worry about stigma of having **autism***	*f=1*		
1st & 2nd Primary School - Mark described	***f=4***	***f=5***	
Emotional-social	***f=4***	***f=5***	
• *SOCIAL - didn't want to go against difficult friend*	*f=1*		
• *SOCIAL - noticing didn't interact well with other kids*	*f=1*	*f=1*	
• *Difficulties accepting changes (during play)*	*f=1*	*f=1*	
• *EMOTIONAL-SOCIAL - didn't have friends or anyone to confide in*		*f=1*	
• *SOCIAL - aspects of beavers and cubs found difficult*		*f=1*	
• *EMOTION - emotionally callous - unable to discuss emotions due to upbringing*	*f=1*	*f=1*	
Secondary School -Mark described	***f=7***	***f=1***	***f=1***
TRANSITIONING	***f=2***		
• *Discussing feelings prior to starting secondary school*	*f=1*		
• *First day of school - found face he recognised and stood by him*	*f=1*		
Academic	***f=2***		
• *ACADEMIC - challenge - public speaking*	*f=1*		
• *'C.S.S.' - wouldn't ask for 1:1 help as not willing to talk to them*	*f=1*		
Emotional-Social	***f=3***	***f=1***	***f=1***
• *SOCIAL - what worried him the most before starting socially*	*f=1*		*f=1*
• *EMOTIONAL - very naive*	*f=1*		
• *EMOTIONAL-SOCIAL - bullying and indirect homophobia from peers*	*f=1*	*f=1*	
Sixth Form - Mark described	***f=1***	***f=1***	
Academic	***f=1***	***f=1***	
• *ACADEMIC - reasonable adjustments - too late for A-level exams as did not bring in **autism** evidence in time*	*f=1*	*f=1*	
University - Mark described	***f=2***		
Academic	***f=1***		
• *ACADEMIC - most scared about*	*f=1*		
Emotional-Social	***f=1***		
• *SLEEP - problems - nocturnal*	*f=1*		
TOTAL	***f=15***	***f=7***	***f=1***

Appendix 4.1 (b): Holistic-Form Results (Mark)

Calculation of Mark's HFA, regressive narrative decline, during each CTT. CTT = core transitioning theme, TST = transitioning subtheme, CS = concurrent stressor, Ac = academic, ES = emotional-social, P = primary, S = secondary, 6 = sixth form, U = university

Calculation of Mark's HFA score: Primary CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (P/S/6/U)	**n = -5**
Minor ES-CS	CS 'being stuck in a negative friendship he wanted to end' (P)	**n = -5**
	CS 'didn't have friends or anyone to confide in' (P)	**n = -5**
	CS 'difficulties accepting change' (P)	**n = -5**
	CS 'difficulties with the social aspects of beavers and cubs' (P)	**n = -5**
	CS 'inability to express his emotions due to upbringing' (P/S/6)	**n = -5**
	CS 'lack of educational referral for assessment' (ASC) (P/S)	**n = -5**
	CS 'struggling socially' (P)	**n = -5**
Major ES-CS	CS/TST(ongoing): 'emotional-social' (P/S/6/U)	**n = -10**
	CS/TST(ongoing): <u>MAJOR CS: </u>'being undiagnosed ASC' (until aged 17 years) (P/S/6)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
Minor negative CFA tone	CFA <u>>despondent</u> (ES) (suggestive of negative experience)	**n = -25**
(iii) State of health for current CTT		
Minor deterioration in state of health (MiD)	MiD in state of health due to an increase in <u>some</u> ES-CS, 'social anxiety', 'inability to express his emotions due to upbringing' and 'being stuck in a negative friendship he wanted to end'.	**n = -50**
	TOTAL Holistic-form analysis SCORE	**n = -135**
Conclusion: Primary CTT demonstrated a regressive narrative decline		

Calculation of Mark’s HFA score: Secondary CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (P/S/6/U)	**n = -5**
Minor ES-CS	CS ‘anxiety about speaking to people on a one-to-one basis due to the intimate personal nature of it’ (S)	**n = -5**
	CS ‘being bullied due to being naïve’ (S)	**n = -5**
	CS ‘confusion about behaving differently to his peers’ (S)	**n = -5**
	CS ‘confusion and social frustration during his puberty years’ (S)	**n = -5**
	CS ‘fitting in with his peers and their mafia mentality whereby you can’t oust a peer to a teacher’ (S)	**n = -5**
	CS ‘inability to express his emotions due to upbringing’ (P/S/6)	**n = -5**
	CS ‘lack of educational referral’ (ASC) (P/S/6)	**n = -5**
	CS ‘not having anyone at school he could talk to about emotional difficulties’ (S)	**n = -5**
	CS ‘peers questioning him as to why he was in a smaller room for exams’ (S)	**n = -5**
	CS ‘making a big social leap’ (S)	**n = -5**
	CS ‘stigma about being autistic and worrying about his peer’s reaction to this’ (S/6)	**n = -5**
	CS ‘suffering indirect homophobia from peers’ (S)	**n = -5**
Major ES-CS	CS/TST(ongoing): ‘emotional-social’ (P/S/6/U)	**n = -10**
	CS/TST(ongoing): <u>MAJOR CS: </u>‘being undiagnosed ASC’ (until aged 17 years) (P/S/6)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
Minor negative CFA tone	CFA <u>>withdrawing</u> (Ac/ES/EST) (suggestive of negative experience)	**n = -25**
Minor negative CFA tone	CFA <u>>worried</u> (ES) (suggestive of negative experience)	**n = -25**
(iii) State of health for current CTT		
Major deterioration in state of health (MaD)	MaD in state of health due to a major increase in ES-CS**,** ‘social anxiety’**,** ‘being bullied due to being naïve’**,** ‘social confusion’**,** ‘stigma about being autistic and worrying about his peer’s reaction to this’**.**	**n = -100**
	TOTAL Holistic-form analysis SCORE	**n = -235**
Conclusion: Secondary CTT demonstrated a regressive narrative decline		

Calculation of Mark's HFA score: Sixth form CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (P/S/6/U)	**n = -5**
Minor ES-CS	CS 'inability to express his emotions due to upbringing' (P/S/6)	**n = -5**
	CS 'stigma about being autistic and worrying about his peer's reaction to this' (S/6)	**n = -5**
Major ES-CS	CS/TST(ongoing): 'emotional-social' (P/S/6/U)	**n = -10**
	CS/TST(ongoing): MAJOR CS: 'being undiagnosed ASC' (until aged 17 years) (P/S/6)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
	n/a	
(iii) State of health for current CTT		
Major improvement in state of health (MaI)	MaI in state of health due to no mention of major ES-CS. Although continued concerns about 'stigma about being autistic and worrying about his peer's reaction to this'	**n = +100**
	TOTAL Holistic-form analysis SCORE	**n = +65**
Conclusion: Sixth form CTT demonstrated a progressive narrative growth		

Calculation of Mark's HFA score: University CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (P/S/6/U)	**n = -5**
Minor ES-CS	CS 'apprehension disclosing autism diagnosis' (U)	**n = -5**
	CS 'being surrounded by emotionally expressive people' (U)	**n = -5**
	CS 'difficulties going to nightclubs because he was then unable to talk to his peers'(U)	**n = -5**
	CS 'difficulties maintaining a regular sleep cycle' (U)	**n = -5**
	CS 'fear of failing academically at university' (U)	**n = -5**
	CS 'not knowing the protocol around others who are being passionate and loving towards each other' (U)	**n = -5**
Major ES-CS	CS/TST(ongoing): 'emotional-social' (P/S/6/U)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
Major positive CFA tone	CFA >positive (Ac/ES/EST/CSS) NB:	**n = +50**
(iii) State of health for current CTT		
Major improvement in state of health (MaI)	MaI in state of health due to no mention of new ongoing ES CS. There was a notable growth, from "emotional callousness to emotional expression", in his ability to express and understand his emotions.	**n = +100**
	TOTAL Holistic-form analysis SCORE	**n = +105**
Conclusion: University CTT demonstrated a progressive narrative growth		

Appendix 4.2 (a): Categorical-Form Results (Karen): Detailed linguistic dialogue data, tones, non-verbals, and frequency of use

Table A: Summary of complete linguistic dialogue used by Karen during interview one and interview two, in the context of themes, sub-themes, and concurrent stressors

	Tones and/or Non-verbals	**Frequency**
DOMINANT PRIMARY	**POSITIVE**	**f=278**
	Gesturing and Tapping hands	f = 78
	Friendly	f = 45
	smiling/laughing	f = 30
	Positive	f = 25
	Happy	f = 22
	Positive & Open communication	f = 78
DOMINANT SECONDARY	**OTHER**	**f=40**
	Hesitant	f = 21
	Playing with hands	f = 19
FACTUAL	Factual	**f = 33**
NEGATIVE		**f=8**
	Twisting hands	f = 5
	Sad	f=3
CONTEMPLATIVE	Contemplative	**f = 24**
SERIOUS	Serious	**f = 23**
TIMID	Timid	**f = 21**

Table B: Positive (relaxed & or happy) Linguistic dialogue used by Karen, during interview one and two, in the context of themes and sub-themes (concurrent stressors)

Themes & or Subthemes	***Gesturing and Tapping hands***	***Friendly***	***Smiling***	***Positive***	***Happy***	***Positive & Open body language***	**Positive tones & non-verbals used**
***ASC**/condition related sub total*	8	8	3	1		8	**f=28**
*Discussing **ASC** assessment*	2	2	2			2	f=8
When parents became aware neuro-diverse	1	1	1			1	f=4
Teaching raising to parents' neurodiversity in Secondary phase	1	1				1	f=3
***ASC** explained to her*	1	1				1	f=3
Feeling about diagnosis at time of interview	1	1		1		1	f=4
Discussing dyspraxia (not officially diagnosed)	1	1				1	f=3
Diagnosis of specific language impairment & sensory processing disorder	1	1				1	f=3
PRIMARY PHASE *sub total*	**5**	**1**	**4**	**4**	**4**	**5**	**f=23**
Academic strengths	1		1	1	1	1	f=5
*Academic **CSS***	1		1	1	1	1	f=5
Social Strengths	1		1	1	1	1	f=5
Emotional strengths	1	1				1	f=3
TRANSITION FROM PRIMARY TO SECONDARY	1		1	1	1	1	f=5
SECONDARY PHASE *sub total*	**12**	**6**	**5**	**5**	**4**	**12**	**f=44**
Academic strengths	1		1	1	1	1	f=5
Social strengths	2		1	2	1	2	f=8
Emotional CS	3	3				3	f=9
Teacher raised neurodiversity to parents	**1**					1	f=2
TRANSITION FROM SECONDARY TO SIXTH FORM PHASE	1		2	1	1	1	f=6
TRANSITION FROM SECONDARY TO SIXTH FORM PHASE: Most excited about	1		1	1	1	1	f=5
TRANSITION FROM SECONDARY TO SIXTH FORM PHASE: secondary school did to support	1	1				1	f=3
TRANSITION FROM SECONDARY TO SIXTH FORM PHASE: sixth form did to support	1	1				1	f=3
TRANSITION FROM SECONDARY TO SIXTH FORM PHASE: family did to support	1	1				1	f=3
SIXTH FORM *sub total*	13	8	6	4	4	13	**f=48**
First day	1	1	1			1	f=4
Academic strengths	2		2	1	2	2	f=9
Academic **CSS**	1	1				1	f=3
Change in learning style - more independent	1	1				1	f=3
Social strengths	1	1		1		1	f=4
Emotional strengths	1	1				1	f=3
Teachers not aware of suspected **ASC**	**1**					1	f=2
TRANSITION FROM SIXTH FORM PHASE TO UNI (BSc.): feelings (independent living/excited about)	**2**		2	2	2	2	f=10
TRANSITION FROM SIXTH FORM PHASE TO UNI (BSc.): sixth form did to prepare	**1**	1				1	f=3
TRANSITION FROM SIXTH FORM PHASE TO UNI (BSc.): uni did to prepare	**1**	1	1			1	f=4
TRANSITION FROM SIXTH FORM PHASE TO UNI (BSc.): parents did to support	1	1				1	f=3
UNI (BSc.) *sub total*	24	7	6	6	6	24	**f=73**
Arriving at uni	1	1				1	f=3
*Discussing **CSS** too late for DSA*	2	1				2	f=5
*NO **CSS** prior to diagnosis*	1					1	f=2
***CSS** after diagnosis*	1					1	f=2
No reasonable adjustments for exams - too later	1					1	f=2
Social strengths	1	1				1	f=3
***CSS** from family*	2		1	1	1	2	f=7
Emotional experiences	1		1	1	1	1	f=5
Emotional CS	1					1	f=2
Academic CS	2					2	f=4
Academic-Emotional CS	1					1	f=2
*Academic **CSS** from uni*	1	1				1	f=3
Expectation about what Uni would be like and really was	1	1				1	f=3
Feelings about independent living	1					1	f=2
Social activities	1		1	1	1	1	f=5
*Social **CSS** from uni*	1	1				1	f=3
*Emotional **CSS** from uni*	1					1	f=2
Academic learner	1		1	1	1	1	f=5
TRANSITION FROM UNI (BSc.) to UNI (MSc.):	1	1				1	f=3
TRANSITION FROM UNI (BSc.) to UNI (MSc.): MSc uni did to help	1		1	1	1	1	f=5
TRANSITION FROM UNI (BSc.) to UNI (MSc.): most excited about - course	1		1	1	1	1	f=5
UNI MSc. *sub total*	**16**	**15**	**6**	**5**	**4**	**16**	**f=62**
Academic **CS**	1	1				1	f=3
Disclosing **ASC**	1	1				1	f=3

Table C: Negative Linguistic dialogue used by Karen, during interview one and two, in the context of themes and sub-themes (concurrent stressors)

Themes & or Subthemes	*Twisting hands*	*Sad*	**Total**
autism - *sub total*	1		f=1
Feeling about diagnosis when first diagnosed	1		
PRIMARY- *sub total*	1		f=1
Social CS	1		
SECONDARY - *sub total*	3		f=3
Academic CS	1		
Social CS	1		
Emotional-social CS	1		
Emotional-Social ***CSS***			
TRANSITION FROM SECONDARY TO SIXTH FORM PHASE: Most scared about			
Sixth Form - *sub total*		1	f=1
TRANSITION FROM SIXTH FORM PHASE TO UNI. (BSc)		1	
UNI (BSc) - *sub total*		2	f=2
Academic CS			
Social CS		2	
Emotional CS			
Academic ***CSS***			
Emotional ***CSS*** *from uni*			
UNI (MSc)- *sub total*			f=0
Emotional **CS**			
Emotional **CSS** - home			
	f = 5	**f=3**	**Total f = 8**

Appendix 4.2 (b): Holistic-Form Results (Karen)

Calculation of Karen’s HFA, regressive narrative decline, during each CTT. CTT = core transitioning theme, TST = transitioning subtheme, CS = concurrent stressor, Ac = academic, ES = emotional-social, P = primary, S = secondary, 6 = sixth form, UBSc = university undergraduate, UMSc = university postgraduate

	Calculation of Karen’s HFA score: Primary CTT	
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major ES-CS	CS/TST(ongoing): ‘emotional-social’ (P/S/6/UBSc/UMSc) - **NB: not appearing to impact ES state of health at this time**	**n = 0**
	CS/TST(ongoing): MAJOR CS: ‘being undiagnosed ASC’ (until aged 20 years) (P/S/6) **NB: not appearing to impact ES state of health at this time**	**n = 0**
(ii) CFA linguistic results (categorising stressors) for current CTT		
	n/a	**n = 0**
(iii) State of health for current CTT		
Stable state of health	Due to no mention of new ES-CS during CTT (apart from initial difficulties making friends)	**n = 0**
	TOTAL Holistic-form analysis SCORE	**n = 0**
Conclusion: Primary CTT demonstrated a stable state of health		

	Calculation of Karen’s HFA score: Secondary CTT	
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (S/UBSc/UMSc)	**n = -5**
	CS ‘difficulty socialising with peers’ (S)	**n = -5**
	CS ‘feeling left out by her peers’ (S)	**n = -5**
	CS ‘feeling like she did not fit in with her peers’ (S)	**n = -5**
	CS ‘feeling that something was different about her but not knowing what’ (S)	**n = -5**
	CS ‘meltdowns due to being frustrated by a challenging activity’ (S)	**n = -5**
	CS ‘not knowing how to deal with stuff…’ (S)	**n = -5**
Major ES-CS	CS/TST(ongoing): ‘emotional-social’ (P/S/6/UBSc/UMSc)	**n = -10**
	CS/TST(ongoing): MAJOR CS: ‘being undiagnosed ASC’ (until aged 20 years) (P/S/6/UBSc)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
Minor negative CFA tone	CFA >twisting hands (Ac/ES) (suggestive of negative experience)	**n = -25**
(iii) State of health for current CTT		
Major deterioration in state of health (MaD)	MaD in state of health due to major increase in ES-CS	**n = -100**
	TOTAL Holistic-form analysis SCORE	**n = -180**
Conclusion: Secondary CTT demonstrated a regressive narrative decline		

Calculation of Karen's HFA score: Sixth form CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major ES-CS	CS/TST(ongoing): 'emotional-social' (P/S/6/UBSc/UMSc)	**n = -10**
	CS/TST(ongoing): MAJOR CS: 'being undiagnosed ASC' (until aged 20 years) (P/S/6/UBSc)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
	n/a	**n = 0**
(iii) State of health for current CTT		
Major improvement in state of health (MaI)	MaI in state of health due to no mention of new ongoing ES-CS	**n = +100**
	TOTAL Holistic-form analysis SCORE	**n = +80**
Conclusion: Sixth form CTT demonstrated a progressive narrative growth		

Calculation of Karen's HFA score: University (BSc) CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (S/UBSc/UMSc)	**n = -5**
Minor ES-CS	CS 'falling out with her friend who she lived with during her second year resulting in her having to live separate from her friends in her third year' ('not seeing friends from before as much', 'not making new friends in her final year') (UBSc)	**n = -5**
	CS 'fear that she couldn't finish her undergraduate degree'	**n = -5**
	CS 'feeling like she did not fit in with her peers and feeling socially awkward' (UBSc)	**n = -5**
Major ES-CS	CS/TST(ongoing): 'emotional-social' (P/S/6/UBSc/UMSc)	**n = -10**
	CS/TST(ongoing): MAJOR CS: 'being undiagnosed ASC' (until aged 20 years) (P/S/6/UBSc)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
Major positive CFA tone	CFA >positive (Ac/ES/EST/CSS)	**n = +50**
(iii) State of health for current CTT		
Minor improvement in state of health (MiI)	MiI in state of health due to overcoming previous ES-CS, and a second year minor ES incident that she was able to resolve	**n = +50**
	TOTAL Holistic-form analysis SCORE	**n = +60**
Conclusion: University (BSc) CTT demonstrated a progressive narrative growth		

Calculation of Karen's HFA score: University (MSc) CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
	n/a	**n = 0**
(ii) CFA linguistic results (categorising stressors)		
	n/a	**n = 0**
(iii) State of health for current CTT		
Major improvement in state of health (MaI)	MaI in state of health due to no mention of ongoing ES-CS	**n = +100**
	TOTAL Holistic-form analysis SCORE	**n = +100**
Conclusion: University (MSc) CTT demonstrated a progressive narrative growth		

Appendix 4.3 (a): Categorical-Form (Jane): Detailed linguistic dialogue data, tones, non-verbals, and frequency of use

Table A: Summary of complete linguistic dialogue used by Jane during interview one and interview two, in the context of themes, sub-themes, and concurrent stressors

	Tones and/or Non-verbals	**Frequency**	**630**
DOMINANT PRIMARY	***Positive***	**f=272**	**43%**
DOMINANT SECONDARY	***Factual***	**f = 115**	**18%**
	serious	f = 101	16%
	'***other***' *(quiet, matter of fact, emotional, contemplation, explanatory, timid, clapping, dramatic, loud, passive, assertive, shock, astonished, exaggerated (facial expression), softening, stubborn, wiggling)*	f=88	14%
	negative	f=54	9%

Table B: Positive Linguistic dialogue used by Jane, during interview one and two, in the context of themes and sub-themes (concurrent stressors)

	Excited	Face lit up	Upbeat	Happy	Relief	Proud	Grateful	Smiling	Laughing	Fondness	Amazed /Awe	Positive tone & non-verbals used
autism												
autism suspected	1	1										f = 2
autism assessment & Diagnosis	1	2	1			1						f = 5
Related Conditions:												
ADHD	2	1		1								f = 4
Dyslexia			1				1					f = 2
Self-harming	1		1			1		3				f = 6
Feelings about autism		1			3			1				f = 5
Others perceptions of autism	3			4	1							f = 8
Meltdowns	3		3	1		1	3	3				f = 14
Primary phase												
Primary Ac challenges			1					3				f = 4
Primary Ac strengths				3		4		1				f = 8
Primary Ac-CSS							1					f = 1
Primary ES challenges	2		1	2				4	4			f = 13
Primary ES-CSS				1								f = 1
Secondary phase												
Secondary Ac challenges	3								1			f = 4
Secondary Ac-CSS	1		3					2				f = 6
Secondary (senior) school transitioning into sixth form (TS6) CSS	1					1		1				f = 3
Secondary ES/MH			1					1				f = 2
Secondary ES challenges	2					1		2				f = 5
Secondary ES strengths			2			1		2	2			f = 7
Sixth form phase												
Sixth form Ac. strengths				1		5	4	5				f = 15
Sixth form Ac-CSS	2		1				7	12		3	2	f = 27
Sixth form college transitioning into university (T6U) CSS			5				1	10	1			f = 17
Sixth Form ES/MH	1		1					1				f = 3
Sixth form ES challenges						2	6	7		3		f = 18
Sixth form ES strengths	2		4			3		6		1		f = 16
Sixth form ES-CSS						1	5	5		4		f = 15
Sixth form SnC			1				1					f = 2
University phase												
University Ac challenges						1						f = 1
University Ac strengths	2					4		4				f = 10
University Ac-CSS	2						2					f = 4
University ES challenges			2					3	1			f = 6
University ES strengths			2	5		12		9				f = 28
University ES-CSS							1	1				f = 2
University SnC			1	1		5		1				f = 8
	f = 29 (-11)	f = 5 (-5)	f = 31 (-6)	f = 19 (-6)	f = 4 (-4)	f = 43 (-3)	f = 32 (-4)	f = 87 (-7)	f = 9	f = 11	f = 2	Total f = 272 (-35)

Table C: Negative Linguistic dialogue used by Jane, during interview one and two, in the context of themes and sub-themes (concurrent stressors)

	Sad	Frustrated	annoyed	despondent	hopeless	**disappointed**	upset	**angry**	confused	vulnerable	withdrawn	terror	**Negative tone & non-verbals used**
autism													
autism suspected			2	1	1								f = 4
Other Conditions:													
Dyslexia		1											f = 1
Self-harming						**1**							f = 1
Feelings about **autism**							1						f = 1
Primary phase													
Primary Ac challenges											1		f = 1
Primary ES challenges							2		3				f = 5
Primary transitioning into Secondary school (TPS)	1												f = 1
Primary SnC											4	1	f = 5
Secondary phase (> negative nonverbals n=32)													
Secondary Ac challenges		1			1	**1**		1	2		1		f = 7
Secondary CSS						**2**							f = 2
Secondary ES challenges		1	2			**3**		8			1		f = 15
Secondary ES (MH) challenges						**3**							f = 3
Secondary ES strengths								2					f = 2
Secondary SnC			3										f = 3
sixth form phase													
Sixth form ES challenges									1				f = 1
university phase													
University Ac challenges		1											f = 1
University SnC										1			f = 1
TIMES USED	1	4 (-1)	7 (-2)	1 (-1)	2 (-1)	**>10 (-1)**	3 (-1)	**>11**	6	1	7	1	f = 54 (-7)

Appendix 4.3 (b): Holistic-Form Results (Jane)

Calculation of Jane's HFA score during each CTT. CTT = core transitioning theme, TST = transitioning subtheme, CS = concurrent stressor, ES = emotional-social, P = primary (I = infant / J = junior), S = secondary, 6 = sixth form, U = university

Calculation of Jane's HFA score: Primary CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (I/J/S/6/U)	**n = -5**
Minor ES-CS	CS 'anorexia (10-17 years)' (J/S/6)	**n = -5**
	CS 'anxiety' (I/J/S/6/U)	**n = -5**
	CS 'being bullied' (I/J/S)	**n = -5**
	CS 'being forced to socialise' (I/J)	**n = -5**
	CS 'being labelled as a problem child' (J)	**n = -5**
	CS 'belief she was different to her peers' (I)	**n = -5**
	CS 'feeling like the odd one out' (J)	**n = -5**
	CS 'parent screaming in her face' (J)	**n = -5**
	CS 'social difficulties' (I/J/6/U)	**n = -5**
	CS 'teacher's negative behaviours towards her' (J/S)	**n = -5**
	CS 'trichotillomania (4-16 years)' (I/J/S)	**n = -5**
Major ES-CS	CS/TST(ongoing): 'emotional-social' (I/J/S/6/U)	**n = -10**
	CS/TST(ongoing): MAJOR CS: 'being undiagnosed ASC' (until aged 16 years) (I/J/S)	**n = -10**
	CS/TST(ongoing): MAJOR CS: 'sensory challenges (SnC)' (I/J/S/6/U)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
	n/a	**n = 0**
(iii) State of health for current CTT		
Minor deterioration in state of health (MiD)	MiD in state of health due to increasing Ac-CS and ES-CS	**n = -50**
	TOTAL Holistic-form analysis SCORE	**n = -140**
Conclusion: Primary CTT demonstrated a regressive narrative decline		

Calculation of Jane’s HFA score: Secondary CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (I/J/S/6/U)	**n = -5**
Minor ES-CS	CS ‘anorexia (10-17 years)’ (J/S/6)	**n = -5**
	CS ‘anxiety’ (I/J/S/6/U)	**n = -5**
	CS ‘being alone’ (S)	**n = -5**
	CS ‘being bullied’ (I/J/S)	**n = -5**
	CS ‘being refused entry into the SEN unit’ (S)	**n = -5**
	CS ‘confusion at being put into exclusion (isolation)’ (S)	**n = -5**
	CS ‘difficulties with social relationships with girls’ (S)	**n = -5**
	CS ‘discrimination against her family by her teachers’ (S)	**n = -5**
	CS ‘emotional-mental health’ (S)	**n = -5**
	CS ‘self-harming’ (S/6)	**n = -5**
	CS ‘social difficulties’ (I/J/6/U)	**n = -5**
	CS ‘social upheaval’ (S)	**n = -5**
	CS ‘suicide attempts’ (S)	**n = -5**
	CS ‘teacher’s negative behaviours towards her’ (J/S)	**n = -5**
	CS ‘trichotillomania (4-16 years)’ (I/J/S)	**n = -5**
Major ES-CS	CS/TST(ongoing): ‘emotional-social’ (I/J/S/6/U)	**n = -10**
	CS/TST(ongoing): MAJOR CS: ‘being undiagnosed ASC’ (until aged 16 years) (I/J/S)	**n = -10**
	CS/TST(ongoing): MAJOR CS: ‘sensory challenges (SnC)’ (I/J/S/6/U)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
Minor negative CFA tone	CFA >negative-disappointed (Ac/Ac-CSS/ES) (suggestive of negative experience)	**n = -25**
Major negative CFA tone	CFA >negative-angry (Ac/ES)	**n = -50**
Major negative CFA tone	CFA >negative (Ac/Ac-CSS/ES/SnC)	**n = -50**
(iii) State of health for current CTT		
Major deterioration in state of health (MaD)	MaD in state of health due to major increase in ES-CS, anxiety, mental health conditions (anorexia, self-harming, suicide attempts), being bullied.	**n = -100**
	TOTAL Holistic-form analysis SCORE	**n = -335**
Conclusion: Secondary CTT demonstrated a regressive narrative decline		

Calculation of Jane’s HFA score: Sixth form CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (I/J/S/6/U)	**n = -5**
Minor ES-CS	CS ‘anorexia (10-17 years)’ (J/S/6)	**n = -5**
	CS ‘anxiety’ (I/J/S/6/U)	**n = -5**
	CS ‘emotional mental health’ (S/6/U)	**n = -5**
	CS ‘having a meltdown’ (6/U)	**n = -5**
	CS ‘“others” stereotypical views of autism’ (6)	**n = -5**
	CS ‘people bitching and talking behind her back’ (6)	**n = -5**
	CS ‘reminiscing about the way she had been treated previously in school’ (6)	**n = -5**
	CS ‘self-harming’ (S/6/U)	**n = -5**
	CS ‘social difficulties’ (I/J/S/6/U)	**n = -5**
	CS ‘social exhaustion’ (6)	**n = -5**
	CS ‘stress’ (6)	**n = -5**
	CS ‘struggled with her autism diagnosis in general’ (6)	**n = -5**
Major ES-CS	CS/TST(ongoing): ‘emotional-social’ (I/J/S/6/U)	**n = -10**
	CS/TST(ongoing): MAJOR CS: ‘sensory challenges (SnC)’ (I/J/S/6/U)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
Major positive CFA tone	CFA >positive (Ac/ES/EST/SnC/CSS)	**n = +50**
(iii) State of health for current CTT		
Major improvement in state of health (MaI)	MaI in state of health major improvement in ES-CS (anorexia, trichotillomania, and suicide attempts stopping, self-harming incidents lessening) following diagnoses (ASD, ADHD, Dyslexia),	**n = +100**
Major improvement in state of health (MaI)	MaI in state of health due to improvement in ES-CS resulting from autism specific CSS provisions provided by specialist autism service	**n = +100**
	TOTAL Holistic-form analysis SCORE	**n = +165**
Conclusion: Sixth form CTT demonstrated a progressive narrative growth		

Calculation of Jane’s HFA score: University CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (I/J/S/6/U)	**n = -5**
Minor ES-CS	CS ‘anxiety’ (I/J/S/6/U)	**n = -5**
	CS ‘argument with flatmates during first term’ (U)	**n = -5**
	CS ‘emotional mental health’ (S/6/U)	**n = -5**
	CS ‘fear of change’ (U)	**n = -5**
	CS ‘having a meltdown’ (6/U)	**n = -5**
	CS ‘living in university accommodation’ (U)	**n = -5**
	CS ‘loneliness’ (U)	**n = -5**
	CS ‘meeting new people’ (U)	**n = -5**
	CS ‘social difficulties’ (I/J/S/6/U)	**n = -5**
	CS ‘social vulnerability’ (U)	**n = -5**
	CS ‘trying not to be too weird’ (U)	**n = -5**
Major ES-CS	CS/TST(ongoing): ‘emotional-social’ (I/J/S/6/U)	**n = -10**
	CS/TST(ongoing): MAJOR CS: ‘sensory challenges (SnC)’ (I/J/S/6/U)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
	n/a	**n = 0**
(iii) State of health for current CTT		
Major improvement in state of health (MaI)	MaI in state of health due to no ongoing increase in Ac-CS and ES-CS	**n = +100**
	TOTAL Holistic-form analysis SCORE	**n = +20**
Conclusion: University CTT demonstrated a progressive narrative growth		

Appendix 4.4 (a): Categorical-Form (Leigh): Detailed linguistic dialogue data, tones, non-verbals, and frequency of use

Table A: Summary of complete linguistic dialogue used by Leigh during interview one and interview two, in the context of themes, sub-themes, and concurrent stressors

	Tones and/or Non-verbals	**Frequency**
Dominant Narrative Primary Tone	**Factual**	**f=26**
Dominant Narrative Secondary Tone	**Positive (**happy, relief, upbeat, pride, joyous, relief, gratitude**)**	**f=23**
Dominant Narrative Secondary Tone	**Other** (Emphasised, Explanatory, Contemplation, Serious, Determined, Resignation, Exasperation, Sincere, Hesitant, passive, despondent, shame)	**f=24**
Narrative Negative Tone	**Negative** (sad, distressed, baffled, stressed)	f=11

Table B: Positive Linguistic dialogue used by Leigh, during interview one and two, in the context of themes and sub-themes (concurrent stressors)

TONE: Positive		
Primary School	**TONE: Happy**	*f=3*
	ES-CS - Describing one friend that he had *ES-CS - Wondering around the playground alone making up things in his head* *ES-CS - Describing best friends as books*	
	TONE: Relief *ES-CS - When dad intervened in bullying incident and child stopped*	*f=1*
	PRIMARY TOTAL POSITIVE TONES	**f=4**
Secondary School	**TONE: Upbeat**	*f=4*
	CSS *- Discussing extremely supportive teachers helping him do well* *Ac-CS - Teaching in a way that was easy to understand/jargon free* *ES-CS - Describing one person could interact with* ***CSS*** *- Teachers preparing him for uni*	
	TONE: Happy *Ac-CS - Talking about his RE teacher*	*f=1*
	SECONDARY TOTAL POSITIVE TONES	**f=5**
Sixth Form	**TONE: Upbeat**	*f=1*
	Ac-CS - Switching from A-Level to BTEC	
	TONE: Pride	*f=3*
	Ac-CS -Discussing the DICE course *Ac-CS - Getting a distinction in BTEC and place on the DICE course* *ES-CS - Toughening up*	
	SIXTH FORM TOTAL POSITIVE TONES	**f=4**
At University (BSc)	**TONE: Upbeat**	*f=1*
	Ac-CS -Specialising in subject of choice	
	TONE: Joyous	*f=2*
	ES-CS - Boost to morale meeting wonderful people *ES-CS - Discussing societies joined*	
	TONE: Pride	*f=2*
	Ac-CS - Being taught by experts in their field *ES-CS - Experience gained from shouldering responsibilities paying bills*	
	TONE: Relief	*f=1*
	ES-CS - Concerns wouldn't fit in which were unfounded	
	TONE: Gratitude	*f=1*

	ES-CS - Being in an environment with people who "oozed passion and compassion"	
	UNI (BSC) TOTAL POSITIVE TONES	**f=7**
autism	**TONE: Happy**	**f=2**
	Discovering how ***autism*** *related to himself*	
	Talking about his echolalia	
Future	**TONE: Relief**	**f=1**
	Channelling his interests into teaching others	
		Total f =23

Table C: Negative Linguistic dialogue used by Leigh, during interview one and two, in the context of themes and sub-themes (concurrent stressors)

		Tone: Negative
	TONE: Sad	**f=5**
Primary school		*f=2*
	Letting their words cut him and how one child tore his clothes	
	Describing being teased	
Secondary School		*f=3*
	Being ignored or told to shut up by peers	
	Peers having nothing to do with him	
	Describing secondary school as toughest time for him socially	
	TONE: Distressed	**f=3**
autism		*f=1*
	Talking about his ***OCD*** *tendencies*	
Secondary School		*f=1*
	Discussing taunts received	
Sixth Form		*f=1*
	Discussing how he struggled with Biology A-Level	
	TONE: Baffled	**f=1**
Eye-sight		*f=1*
	That the school hadn't noticed his short-sightedness	
	TONE: Stressed	**f=2**
At University (BSc)		*f=2*
	Shouldering the responsibilities of paying bills in student house	
	Discussing incident in 3rd year	
		Total f =11

Appendix 4.4 (b): Holistic-Form Results (Leigh)

Calculation of Leigh's holistic-form analysis score during each CTT. CTT = core transitioning theme, Ac = academic, CS = concurrent stressor, ES = emotional-social, P = primary, S = secondary, 6 = sixth form, UBSc = university undergraduate, UMSc = university postgraduate

Calculation of Leigh's HFA score: Primary CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (P/S/6/UBSc/UMSc)	**n = -5**
Minor ES-CS	CS 'being bullied' (P/S)	**n = -5**
	CS 'being severely short-sighted' (P)	**n = -5**
	CS 'feeling different to his peers' (P/S)	**n = -5**
	CS 'his clothes being torn' (P)	**n = -5**
	CS 'loneliness' (P)	**n = -5**
	CS 'needing to be reminded to eat during a primary school trip' (P)	**n = -5**
Major ES-CS	CS/TST(ongoing): 'emotional-social' (P/S/6/UBSc/UMSc)	**n = -10**
	CS/TST(ongoing): <u>MAJOR CS:</u> 'being undiagnosed ASC' (until aged 14 years) (P/S)	**n = -10**
	CS/TST(ongoing): <u>MAJOR CS:</u> 'worrying about others' (P/S/6/UBSc/UMSc)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
	n/a	**n = 0**
(iii) State of health for current CTT		
Minor deterioration in state of health (MiD)	MiD in state of health due to a minor increase in some ES-CS, being bullied, eye problems, loneliness, and increasing social anxiety	**n = -50**
	TOTAL Holistic-form analysis SCORE	**n = -115**
Conclusion: Primary CTT demonstrated a regressive narrative decline		

Calculation of Leigh's HFA score: Secondary CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (P/S/6/UBSc/UMSc)	**n = -5**
Minor ES-CS	CS 'being bullied' (P/S)	**n = -5**
	CS 'being dismissed by his peers' (S)	**n = -5**
	CS 'being ignored by his peers' (S)	**n = -5**
	CS 'being shouted at by his peers' (S)	**n = -5**
	CS 'being told to shut up by his peers' (S)	**n = -5**
	CS 'feeling different to his peers' (P/S)	**n = -5**
	CS 'feeling downtrodden' (S)	**n = -5**
	CS 'feelings of shame that he was not able to stand up for himself' (S)	**n = -5**
	CS 'peers who did not want to learn in class' (S)	**n = -5**
	CS 'social difficulties with peers' (S)	**n = -5**
Major ES-CS	CS/TST(ongoing): 'emotional-social' (P/S/6/UBSc/UMSc)	**n = -10**
	CS/TST(ongoing): <u>MAJOR CS:</u> 'being undiagnosed ASC' (until aged 14 years) (P/S)	**n = -10**
	CS/TST(ongoing): <u>MAJOR CS:</u> 'worrying about others' (P/S/6/UBSc/UMSc)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
Major negative CFA tone	CFA >negative (ES)	**n = -50**
(iii) State of health for current CTT		
Major deterioration in state of health (MaD)	MaD in state of health due to major increase in ES-CS, feeling 'downtrodden', increasing social difficulties, and possible shame for not 'standing up for himself'.	**n = -100**
	TOTAL Holistic-form analysis SCORE	**n = -235**
Conclusion: Secondary CTT demonstrated a regressive narrative decline		

Calculation of Leigh's HFA score: Sixth form CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (P/S/6/UBSc/UMSc)	**n = -5**
Major ES-CS	CS/TST(ongoing): 'emotional-social' (P/S/6/UBSc/UMSc)	**n = -10**
	CS/TST(ongoing): MAJOR CS: 'worrying about others' (P/S/6/UBSc/UMSc)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
	n/a	**n = 0**
(iii) State of health for current CTT		
Major improvement in state of health (MaI)	MaI in state of health due to no mention of new ongoing ES-CS	**n = +100**
	TOTAL Holistic-form analysis SCORE	**n = +75**
Conclusion: Sixth form CTT demonstrated a progressive narrative growth		

Calculation of Leigh's HFA score: University (BSc) CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (P/S/6/UBSc/UMSc)	**n = -5**
Minor ES-CS	CS 'a phobia about world news' ('undiagnosed OCD') (UBSc/UMSc)	**n = -5**
	CS 'a phobia of filling out forms' ('undiagnosed OCD') (UBSc/UMSc)	**n = -5**
	CS 'a phobia of paying bills' ('undiagnosed OCD') (UBSc/UMSc)	**n = -5**
	CS 'anxiety about world affairs' ('undiagnosed OCD') (UBSc/UMSc)	**n = -5**
	CS 'having to take on the responsibility of paying the household bills' (UBSc/UMSc)	**n = -5**
Major ES-CS	CS/TST(ongoing): 'emotional-social' (P/S/6/UBSc/UMSc)	**n = -10**
	CS/TST(ongoing): MAJOR CS: 'worrying about others' (P/S/6/UBSc/UMSc)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
Major positive CFA tone	CFA >positive (Ac/ES)	**n = +50**
(iii) State of health for current CTT		
Minor deterioration in state of health (MiD)	MiD in state of health due to new ES-CS, OCD related symptoms and phobias	**n = -50**
	TOTAL Holistic-form analysis SCORE	**n = -50**
Conclusion: University (BSc) CTT demonstrated a regressive narrative decline		

Calculation of Leigh’s HFA score: University (MSc) CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	Appeared to remain stable	**n = 0**
Minor ES-CS	CS ‘a phobia about world news’ (‘undiagnosed OCD’) (UBSc/UMSc) Appeared to remain stable	**n = 0**
	CS ‘a phobia of filling out forms’ (‘undiagnosed OCD’) (UBSc/UMSc) Appeared to remain stable	**n = 0**
	CS ‘a phobia of paying bills’ (‘undiagnosed OCD’) (UBSc/UMSc) Appeared to remain stable	**n = 0**
	CS ‘anxiety about world affairs’ (‘undiagnosed OCD’) (UBSc/UMSc) Appeared to remain stable	**n = 0**
	CS ‘having to take on the responsibility of paying the household bills’ (UBSc/UMSc) Appeared to remain stable	**n = 0**
Major ES-CS	CS/TST(ongoing): ‘emotional-social’ (P/S/6/UBSc/UMSc) Appeared to remain stable	**n = 0**
	CS/TST(ongoing): MAJOR CS: ‘worrying about others’ (P/S/6/UBSc/UMSc) Appeared to remain stable	**n = 0**
(ii) CFA linguistic results (categorising stressors)		
	n/a	**n = 0**
(iii) State of health for current CTT		
Stable state of health	Stable state of health due to no new ES-CS, OCD related symptoms and phobias	**n = 0**
	TOTAL Holistic-form analysis SCORE	**n = 0**
Conclusion: University (MSc) CTT demonstrated a stable narrative		

Appendix 4.5 (a): Categorical-Form (Andy): Detailed linguistic dialogue data, tones, non-verbals, and frequency of use

Table A: Summary of complete linguistic dialogue used by Andy during interview one and interview two, in the context of themes, sub-themes, and concurrent stressors

	Tones and/or Non-verbals	**Frequency**
Dominant Primary Tone	**Factual**	**f=117**
Dominant Secondary Tone	**Negative**	**f=82**
Positive	Positive	f=79
Hesitant	Hesitant	f=36

Table B: Negative Linguistic dialogue used by Andy, during interview one and two, in the context of themes and sub-themes (concurrent stressors)

	Negative Linguistic dialogue: TOTAL	**Worried**	**Sad (looking down/closed communication, withdrawing into self)**	**Very quiet tone**	**Nervous. Closed Communication, leaning back, head leaning back, leaning away from the interviewer.**
Discussing autism	***f=15***	*f=4*	*f=3*	*f=7*	*f=1*
• *Being undiagnosed ASC*				*f=3*	
• *Concern about having something wrong with him*				*f=1*	
• *Concerned about having something different about him*		*f=1*	*f=1*	*f=1*	*f=1*
• *'social difficulties with peers'*		*f=1*	*f=1*	*f=1*	
• *'giving eye contact'*					
• *'difficulties communicating through speech'*					
• *'feeling socially awkward'*					
• *'didn't want to stand out'*		*f=1*	*f=1*	*f=1*	
• *'fear of being talked down to or treated as if not intelligent'*					
• *autism – feelings about diagnosis*					
• *'about having a mental health condition'*					
• *Doesn't want a mental health condition*					
• *Wants to be considered normal*					
• *Doesn't want to stand out*					
• *Wants to be able to have a reasonable conversation*					
• *Doesn't want to be talked down to or treated like unintelligent*					
• *How autism label it is used to insult people online*		*f=1*			
Discussing Depression	***f=1***		*f=1*		
• *How he broke down at certain points*			*f=1*		
2nd Primary school - Describing	***f=12***	*f=2*	*f=2*	*f=6*	*f=2*
• *What he did outside of school (ES)*				*f=1*	
• *Not being comfortable in social group activities (ES)*			*f=1*	*f=1*	*f=1*
• *How he voiced to mum he was uncomfortable in group situations (age 10) (ES)*				*f=1*	
• *EMOTIONALLY*		*f=1*	*f=1*	*f=1*	*f=1*
• *SHY – didn't talk much (ES)*					
• *How he was uncomfortable drawing attention to himself (ES)*		*f=1*		*f=1*	
• *How he was emotionally timid (ES)*				*f=1*	
1st Secondary School - Describing	***f=27***	*f=6*	*f=8*	*f=8*	*f=5*

- *SOCIALLY-EMOTIONALLY - Hated 1st high school attended – "hell on earth" – "horrible people" – "bully some" – went there for 2 years then moved to a new school… (ES)*		f=1	f=1	f=1	f=1
- *EMOTIONALLY – really sad (ES)*		f=1	f=1	f=1	f=1
- *how he thought the school would be ok as long as he had his 2 friends (ES)*			f=1		
- *Was scared he would be bullied in school (ES)*			f=1	f=1	
- *How he worried about the jump academically (Ac)*		f=1		f=1	
- *how he found it hard when the teacher's raised their voices (SnC)*		f=1	f=1	f=1	f=1
- *Bullying and where to go for a quiet place during break times (ES)*		f=1	f=1	f=1	f=1
- *Two friends who "turned their backs" on him (ES)*		f=1	f=1	f=1	f=1
- *1st SECONDARY SCHOOL EMOTIONALLY – 100% SAD (ES)*			f=1	f=1	
2nd Secondary School - Describing	*f=0*				
Sixth Form - Describing	*f=6*		f=2	f=2	f=2
- *What he was most scared about in sixth form - being on his own (ES)*			f=1	f=1	f=1
- *EMOTIONAL TRIGGERS – being alone -being ignored (ES)*			f=1	f=1	f=1
University - describing	*f=21*	f=2	f=7	f=5	f=7
- *First term of uni - EMOTIONAL —-first accommodation – didn't like – least happy part of his time at uni (ES)*		f=1	f=1	f=1	f=1
- *Prior to starting most SCARED about…?*			f=2	f=2	f=2
- *ACADEMIC – academic level – amount of work*					
- *SOCIAL - being alone (Ac/ES)*					
- *Any barriers???*			f=1	f=1	f=1
- *SOCIAL - going to social events (ES)*					
- *EMOTIONS - first year – 50% sad – not spending a lot of time with his friends from Christian union at this point (SOCIAL TRIGGER) (ES)*			f=1		f=1
- *' worry that lectures knowing about autism would result in being treated differently from peers' (ES)*		f=1			
- *EMOTIONAL/ SOCIAL DIFFICULTIES – impacted his ability to want to do work (ES)*			f=1		f=1
- *GREATEST CHALLENGE EMOTIONALLY AT UNI – spending majority of time alone – not being able to talk to people (ES)*			f=1	f=1	f=1
TOTAL	*f=82*	*f=14*	*f=23*	*f=28*	*f=17*

Table C: Positive Linguistic dialogue used by Andy, during interview one and two, in the context of themes and sub-themes (concurrent stressors)

	Positive open communication, leaning forward, towards interviewer
Discussing autism	*f=8*
• *Being undiagnosed ASC*	*f=3*
• *Getting diagnosed*	*f=2*
• *'social difficulties with peers'*	*f=1*
• *'giving eye contact'*	
• *'difficulties communicating through speech'*	
• *'feeling socially awkward'*	
• *How autism is linked with depression*	*f=1*
• *How he needs to do more research on his autism and what it means*	*f=1*
2nd Primary school - Describing	*f=10*
• *What it was like (ES)*	*f=1*
• *First memory, first piece of work (Ac)*	*f=1*
• *Friendships in primary school (ES)*	*f=1*
• *Academic demands (Ac)*	*f=1*
• *Favourite subject math (Ac)*	*f=1*
• *Learning about different cultures and history (Ac)*	*f=1*
• *Academic support - from smaller group of peers (Ac-CSS)*	*f=1*
• *Play time and interaction with peers (ES)*	*f=1*
• *What he did outside of school (ES)*	*f=1*
• *SOCIALLY - Last year of primary – football – talking about certain subjects (ES)*	*f=1*
1st Secondary School - Describing	*f=0*
2nd Secondary School - Describing	*f=10*
• *How he got along well with his new classmates (ES)*	*f=1*
• *How previous he had visited this school (EST)*	*f=1*
• *Did well academically but put in foundation years (Ac)*	*f=1*
• *No real academic support - had to be independent - but classes smaller (Ac-CSS)*	*f=1*
• *How because it was a small school more able to interact with others (ES)*	*f=1*
• *How he had good friendships (ES)*	*f=1*
• *How he hung out with peers outside of school (ES)*	*f=1*
• *His mental health, bouts of depression, sad at times (ES)*	*f=1*
• *Triggers: if felt he was left out or ignored by peers (ES)*	*f=1*
• *Triggers: social (ES)*	*f=1*
Sixth Form - Describing	*f=16*
• *How sixth form prepared him for A-level classes (Ac)*	*f=1*
• *memories of first day of sixth form (ES)*	*f=1*
• *things he was most excited about going to sixth form - specialising in specialist subjects (Ac)*	*f=1*
• *How his mum pressured him to join social groups (ES)*	*f=1*
• *doing assignments / getting work in on time / struggle to understand work set (Ac/ES)*	*f=2*
• *student support services helped him with his work (CSS)*	*f=1*
• *academic additional support - extra time - computer - bathroom breaks (CSS)*	*f=1*
• *ACADEMIC ADDITIONAL SUPPORT - computer - Due to the fact he was struggling to move on to the next question – made it easier for him to do this and then return to the unanswered question (CSS)*	*f=1*
• *SOCIALLY - two people interacted with the most – a lot of the time alone – went to student support area during breaks – local village – the park – go for a walk (ES)*	*f=1*
• *EMOTIONALLY - better than high school – still felt sad due to loneliness (ES)*	*f=1*
• *SIXTH FORM COLLEGE EMOTIONALLY - 25% SAD (ES)*	*f=1*
• *had study support and emotional, social support (CSS)*	*f=1*
• *SOCIAL / EMOTIONAL SUPPORT - area students could go (CSS)*	*f=1*
• *Sixth form support – living skills / social skills / choosing degree and uni / personal statement / given spare time to go to open days (EST) (CSS)*	*f=2*

University - describing	*f=35*
• *EMOTIONAL —-nerve wrecking away from home for first time… depressing room (ES)*	*f=1*
• *Prior to starting most excited about…?*	*f=1*
• *ACADEMICALLY —--learning mostly (Ac)*	
• *EMOTIONAL —-first month of uni – was struggling – mum realised – approach wellbeing – got support once had diagnosis letter confirming autism (ES)*	*f=1*
• *autism – diagnosis / Access to specific autism support – halfway through second month (ES)*	*f=1*
• *SUPPORT —following autism diagnosis – met with autism practitioner once a week to talk about uni (CSS)*	*f=1*
• *ACADEMIC —following autism diagnosis – REASONABLE ADJUSTMENTS IN place – computer / smaller room / rest breaks / extra time (CSS)*	*f=1*
• *DSA ACADEMIC FUNDING —following autism diagnosis – few weeks later applied for DSA – they funded – laptop – recorder – equipment – study skills support (CSS)*	*f=1*
• *DSA autism SPECIFIC/MH FUNDING —specialist autism mentor (CSS)*	*f=1*
• *SOCIAL IMAGINATION –prior to starting -was uni what he expected it to be… thought it would be mainly about academic, as well as social and independent development (ES)*	*f=1*
• *ACADEMIC BIGGEST CHALLENGE -seminars (Ac/ES)*	*f=2*
• *ACADEMIC SUPPORT -WITH seminars – recommended how to interact and put point of view forward – eventually got on well enough (CSS)*	*f=1*
• *SOCIALLY BIGGEST CHALLENGE -developing new bonds and relationships – mainly relying on Christian union for this (ES)*	*f=1*
• *SOCIAL INTERACTIONS -joined law and bar society and Christian union society - made some good friends still in contact with (ES)*	*f=1*
• *Living independently - first time - prepared by learning – basic cooking – living skills – looking after a house and himself – washing - money management (ES)*	*f=1*
• *SOCIAL - changed accommodation – due to partying – not a great environment for him - people lived with were ok (ES)*	*f=1*
• *EMOTIONAL - in new accommodation – FELT A LOT BETTER – LESS DEPRESSING (ES)*	*f=1*
• *ACADEMIC CHALLENGES & additional support (DSA) - needed study skills support – once a week – planning work – learning terms (CSS)*	*f=1*
• *ACADEMIC Support – dept. - personal tutor- met once a term – talk about academic issues (CSS)*	*f=1*
• *ACADEMIC teaching/ learning style - longer lectures and use of seminars – more details – had to keep “ears open” “pen steady” (Ac)*	*f=1*
• *ACADEMIC support – audio device (DSA) - finds it helpful to record lectures and play this back (CSS)*	*f=1*
• *autism / SOCIAL SUPPORT GROUPS – Eureka autism uni social group – weekly meet-ups. (CSS)*	*f=1*
• *SOCIAL EMOTIONAL SUPPORT FAMILY – talk to mum everyday (CSS)*	*f=1*
• *SUPPORT (DSA autism MENTOR) – HELPED – expand social skills, academic understanding, fit in more with uni life. (CSS)*	*f=1*
• *MH– COUNSELLING SERVICE - HELPED – open up about feelings as well as attending anxiety talks and discussing depression (CSS)*	*f=1*
• *EMOTIONAL / MH– overall – 40% sad and 60% okay at university (ES)*	*f=1*
• *GREATEST CHALLENGE ACADEMICALLY AT UNI – EXAMS – amount of detail needs to write – self-study (Ac/ES)*	*f=2*
• *GREATEST CHALLENGE SOCIALLY AT UNI – keeping a conversation going – participating in groups (ES)*	*f=1*
• *GREATEST ACHIEVEMENT OVERALL AT UNI – getting through the 3 years and getting his degree (Ac/ES)*	*f=2*
• *GREATEST ACHIEVEMENT SOCIALLY AT UNI – cu friendships (ES)*	*f=1*
• *GREATEST ACHIEVEMENT EMOTIONALLY AT UNI – ACCEPTING THERE'S A PROB AND TRYING TO FIX IT – depression and (ES)*	*f=1*
• *GREATEST ACHIEVEMENT independent living AT UNI – HEALTHY LIFESTYLE (ES)*	*f=1*
• *CO-MORBID: Depression – diagnosed during 3rd year of uni – medication and access to services / 'S. - post depression diagnosis - access to medication and support' (ES)*	*f=1*
TOTAL	*f=79*

Appendix 4.5 (b): Holistic-Form Results (Andy)

Calculation of Andy’s holistic-form analysis score during each CTT. CTT = core transitioning theme, Ac = academic, CS = concurrent stressor, ES = emotional-social, 2nd P = primary, 1st S = first secondary, 2nd S = second secondary, 6 = sixth form, U. = university

Calculation of Andy’s HFA score: 2nd Primary CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (2nd P/1st S/2nd S/6/U)	**n = -5**
Minor ES-CS	CS ‘anxiety telling mum he did not want to go to social groups’ (2nd P)	**n = -5**
	CS ‘discomfort in social groups’ (2nd P)	**n = -5**
	CS ‘not wanting to raise any concerns about himself from others’ (2nd P)	**n = -5**
	CS ‘shyness’ (2nd P)	**n = -5**
Major ES-CS	CS/TST(ongoing): ‘emotional-social’ (P/S/6/UBSc/UMSc)	**n = -10**
	CS/TST(ongoing): MAJOR CS: ‘being undiagnosed ASC’ (until aged 19 years) (2nd P/1st S/2nd S/6/U)	**n = -10**
	CS’/TST (ongoing): MAJOR CS: ‘fear about standing out from his peers’ (2nd P/1st S/2nd S/6/U)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
	n/a	**n = 0**
(iii) State of health for current CTT		
Minor deterioration in state of health (MiD)	MiD in state of health due to an increase in some ES-CS, particularly social anxiety	**n = -50**
	TOTAL Holistic-form analysis SCORE	**n = -105**
Conclusion: 2nd Primary CTT demonstrated a regressive narrative decline		

Calculation of Andy’s HFA score: 1st Secondary CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (2nd P/1st S/2nd S/6/U)	**n = -5**
Minor ES-CS	CS ‘100% sadness’ (1st S)	**n = -5**
	CS ‘being bullied’ (1st S)	**n = -5**
	CS ‘being timid’ (1st S)	**n = -5**
	CS ‘losing friendships’ (1st S)	**n = -5**
	CS ‘low mood’ (1st S)	**n = -5**
	CS ‘not knowing where to go during break times to avoid bullies and for a quiet space’ (1st S)	**n = -5**
	CS ‘peers who didn’t want to learn’ (1st S)	**n = -5**
	CS ‘unable to make new friends’ (1st S)	**n = -5**
Major ES-CS	CS/TST(ongoing): ‘emotional-social’ (P/S/6/UBSc/UMSc)	**n = -10**
	CS/TST(ongoing): MAJOR CS: ‘being undiagnosed ASC’ (until aged 19 years) (2nd P/1st S/2nd S/6/U)	**n = -10**
	CS’/TST (ongoing): MAJOR CS: ‘fear about standing out from his peers’ (2nd P/1st S/2nd S/6/U)	**n = -10**
	CS/TST: ‘when people shouted’ (1st S)	**n= -10**
(ii) CFA linguistic results (categorising stressors)		
Major negative CFA tone	CFA >negative (ES)	**n = -50**
(iii) State of health for current CTT		
Major deterioration in state of health (MaD)	MaD in state of health due to a major increase in ES-CS, feeling “100%” sadness”, being bullied, increasing fears, ‘low mood’ and sound sensitivities causing distress	**n = -100**
	TOTAL Holistic-form analysis SCORE	**n = -235**
Conclusion: 1st Secondary CTT demonstrated a regressive narrative decline		

Calculation of Andy’s HFA score: 2nd Secondary CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (2nd P/1st S/2nd S/6/U)	**n = -5**
Minor ES-CS	CS ‘50% sadness’ (2nd S)	**n = -5**
	CS ‘being ignored’ (2nd S/6)	**n = -5**
	CS ‘being left out by peers’ (2nd S)	**n = -5**
	CS ‘depressive symptoms’ (2nd S/6/U)	**n = -5**
	CS ‘sad days’ (2nd S)	**n = -5**
	CS ‘social difficulties with peers’ (2nd S)	**n = -5**
Major ES-CS	CS/TST(ongoing): ‘emotional-social’ (P/S/6/UBSc/UMSc)	**n = -10**
	CS/TST(ongoing): MAJOR CS: ‘being undiagnosed ASC’ (until aged 19 years) (2nd P/1st S/2nd S/6/U)	**n = -10**
	CS’/TST (ongoing): MAJOR CS: ‘fear about standing out from his peers’ (2nd P/1st S/2nd S/6/U)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
	n/a	
(iii) State of health for current CTT		
Major improvement in state of health (MaI)	MaI in state of health due to major improvement in ES-CS, feeling “50%” sadness versus “100%” in the previous phase	**n = +100**
Major improvement in state of health (MaI)	MaI in state of health due to no mention of anxieties or fears, although onset of depressive symptoms.	**n = +100**
	TOTAL Holistic-form analysis SCORE	**n = +135**
Conclusion: 2nd Secondary CTT demonstrated a progressive narrative growth		

Calculation of Andy’s HFA score: Sixth form CTT		
	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	‘CS Ongoing major Ac-CS (2nd P/1st S/2nd S/6/U)	**n = -5**
Minor ES-CS	CS ‘25% sadness’ (6)	**n = -5**
	CS ‘being ignored’ (2nd S/6)	**n = -5**
	CS ‘depressive symptoms’ (2nd S/6/U)	**n = -5**
	CS ‘fear of being alone’ (6)	**n = -5**
	CS ‘not wanting to join social groups’ (6)	**n = -5**
Major ES-CS	CS/TST(ongoing): ‘emotional-social’ (P/S/6/UBSc/UMSc)	**n = -10**
	CS/TST(ongoing): MAJOR CS: ‘being undiagnosed ASC’ (until aged 19 years) (2nd P/1st S/2nd S/6/U)	**n = -10**
	CS’/TST (ongoing): MAJOR CS: ‘fear about standing out from his peers’ (2nd P/1st S/2nd S/6/U)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
	n/a	**n = 0**
(iii) State of health for current CTT		
Major improvement in state of health (MaI)	MaI in state of health due to continued major improvement in ES-CS, feeling “25%” sadness versus “50%” in the previous phase, only one mention of fears, although continuation of depressive	**n = +100**
	TOTAL Holistic-form analysis SCORE	**n = +40**
Conclusion: Sixth form CTT demonstrated a progressive narrative growth		

Calculation of Andy's HFA score: University CTT

	Definition	**Score**
(i) Previously identified CS (from HCA and CCA results)		
Major Ac-CS (impacting state of health)	CS Ongoing major Ac-CS (2nd P/1st S/2nd S/6/U)	**n = -5**
Minor ES-CS	CS '40% sadness for 2nd and 3rd year of university'(U)	**n = -5**
	CS '50% sadness for first year of university' (U)	**n = -5**
	CS 'autism being used as a term used to insult others online' (U)	**n = -5**
	CS 'being away from home for the first time' (U)	**n = -5**
	CS 'being diagnosed with Autism' (U)	**n = -5**
	CS 'concern about lecturers treating differently to peers because of autism diagnosis' (U)	**n = -5**
	CS 'depressive symptoms (2nd S/6/U)	**n = -5**
	CS 'difficulties developing new bonds and relationships with academic peers' (U)	**n = -5**
	CS 'difficulties going to social events' (U)	**n = -5**
	CS 'difficulties keeping a conversation going' (U)	**n = -5**
	CS 'difficulties participating in groups' (U)	**n = -5**
	CS 'difficulties when peers drink and party' (U)	**n = -5**
	CS 'emotional-social difficulties impacted desire to do academic work' (U)	**n = -5**
	CS 'fear about ability to have a reasonable conversation' (U)	**n = -5**
	CS 'fear about having a mental health condition' (U)	**n = -5**
	CS 'fear of being alone' (U)	**n = -5**
	CS 'fear of being talked down to or treated as if not intelligent' (U)	**n = -5**
	CS 'fear that others would not consider him normal' (U)	**n = -5**
	CS 'fear that people would interact with him differently because of his autism diagnosis' (U)	**n = -5**
	CS 'feeling depressed because of the student accommodation' (U)	**n = -5**
	CS 'mood swings' (U)	**n = -5**
	CS 'not being able to talk to people' (U)	**n = -5**
	CS 'running out of money by end of term due to overspending' (U)	**n = -5**
	CS 'spending majority of time alone' (U)	**n = -5**
Major ES-CS	CS/TST(ongoing): 'emotional-social' (P/S/6/UBSc/UMSc)	**n = -10**
	CS/TST(ongoing): MAJOR CS: 'being undiagnosed ASC' (until aged 19 years) (2nd P/1st S/2nd S/6/U)	**n = -10**
	CS'/TST (ongoing): MAJOR CS: 'fear about standing out from his peers' (2nd P/1st S/2nd S/6/U)	**n = -10**
(ii) CFA linguistic results (categorising stressors)		
Major positive CFA tone	CFA >positive (Ac/ES/CSS)	**n = +50**
(iii) State of health for current CTT		
Major deterioration in state of health (MaD)	MaD in state of health due to major ES-CS, feeling "50%" sadness in 1st year and "40%" sadness the rest of university, versus "25%" in the previous phase, several major Ac-CS and social fears, continuation of depressive symptoms, resulting in diagnosis of depression, and mood swings..	**n = -100**
	TOTAL Holistic-form analysis SCORE	**n = -205**

Conclusion: University CTT demonstrated a regressive narrative decline

Appendix 5.1: Correlations, patterns, and relationships among participants' data during the primary CTT

Table (a)

	Frequency category occurrence of concurrent stressors and concurrent stressor support during the primary CTT
Major Ac-CS (impacting state of health)	
	‘**English language**’(Mark, Jane, Leigh) ‘**following instructions**’(Leigh) ‘**handwriting**’(Mark, Jane, Andy) ‘**increased academic demands**’(Jane) ‘**math**’(Mark, Leigh) ‘**rigid need to complete work in a certain manner**’(Leigh) ‘**time constraints**’(Leigh, Andy)
Total	$f = 13$
Major ES-CS	
	‘**being undiagnosed ASC**’(Mark, Karen, Jane, Leigh, Andy) ‘**fear about standing out from his peers**’(Andy) ‘**sensory challenges**’ (SnC)(Jane) ‘**worrying about others**’(Leigh)
Total	$f = 8$
Minor ES-CS	
	‘**abuse from peers parent**’(Jane) ‘**being bullied**’(Jane, Leigh) ‘**being labelled as a problem child**’(Jane) ‘**being undiagnosed**’ with ADHD(Jane) ‘**being undiagnosed**’ with anxiety disorder(Jane) ‘**being undiagnosed**’ with depression(Andy) ‘**being undiagnosed**’ with dyslexia(Jane) ‘**being undiagnosed**’ with dyspraxia/DCD(Karen) ‘**being undiagnosed**’ with OCD(Leigh) ‘**changes**’(Mark) ‘**expressing emotions**’(Mark) ‘**feeling different to peers**’(Jane, Leigh) ‘**friendships**’(Mark, Karen, Jane) ‘**groups**’(Mark, Andy) ‘**lacking appropriate support from school during a school trip**’(Leigh) ‘**loneliness**’(Leigh) ‘**not wanting to draw attention to self**’ (Andy) ‘**shyness**’(Andy) ‘**social difficulties**’(Mark, Jane) ‘**teacher's negative behaviours towards her**(Jane) ‘**undiagnosed ASC**’(Mark) (Mark emphasised other difficulties associated with this such as living in a household that did not accept that he could have autism) ‘**vision problems**’(Leigh)
Total	$f = 28$
Mental health CS	
	‘**anorexia**’(Jane) ‘**anxiety**’(Jane) ‘**trichotillomania**’(Jane)
Total	$f = 3$
Combined CS frequency	
Total	$f = 52$

Table (b)

Primary CTT: Correlations, patterns, and relationships amongst participant data					
	Mark	**Karen**	**Jane**	**Leigh**	**Andy**
(i) Previously identified CS total score	n = - 60	-	n = -90	n = - 65	n = - 55
(ii) CFA (nonverbal) total score	n = - 25	-	-	-	-
(iii) State of health total score	n = - 50 (MiD)	-	n = - 50 (MiD)	n = - 50 (MiD)	n = - 50 (MiD)
HFA total score: Narrative progression or regression	n = - 135 (regressive narrative decline)	n = 0 (stable)	n = - 140 (regressive narrative decline)	n = - 115 (regressive narrative decline)	n = - 105 (regressive narrative decline)

CTT = core transitioning theme, TST = transitioning subtheme, MiD. = minor deterioration in state of health, Ac = Academic, ES = emotional-social, EST - emotional-social transitioning, CSS = concurrent stressor support

Appendix 5.2: Correlations, patterns, and relationships among participants’ data during the secondary CTT

Table (a)

	Frequency category occurrence of concurrent stressors and concurrent stressor support during the secondary CTT
EST-CS	
	‘anxiety about so much change’(Mark)
	‘anxiety about how to make new friends’(Mark)
	‘anxiety about what to expect in new school’(Mark)
	‘apprehensive due to the social upheaval’(Jane)
	‘being forced to have a shower during PE’(Leigh) (worried about this)
	‘changing schools was nerve wrecking’(Andy 2nd S)
	‘fear about the academic jump’(Andy 1st S)
	‘fear of being bullied in new school’(Andy 1st S)
	‘Lack of explicit instructions on how to interact and communicate with peers’(Mark)
Total	*f* = 9
Major Ac-CS (impacting state of health)	
	‘belief must get A grades to be successful’(Karen)
	‘English language’(Mark, Jane)
	‘handwriting’(Mark)
	‘learning topics not interested in’(Leigh)
	‘math’(Leigh, Andy 2nd S)
	‘PE’ (physical education) (Karen)
	‘priority given to core subjects’(Jane)
	‘time constraints’(Mark, Leigh)
Total	*f* = 11
Major ES-CS	
	‘being undiagnosed ASC’(Mark, Karen, Jane, Leigh, Andy)
	‘fear about standing out from his peers’(Andy)
	‘sensory challenges’ (SnC)(Jane)
	‘when people shouted’(Andy 1st S)
	‘worrying about others’(Leigh)
Total	*f* = 9
Minor ES-CS	
	‘being alone’(Jane)
	‘being bullied’(Mark, Jane, Leigh, Andy 1st S)
	‘being dismissed by peers’(Leigh)
	‘being ignored by peers’(Leigh, Andy 2nd S)
	‘being left out by peers’(Karen, Andy 2nd S)
	‘being refused entry into SEN unit’(Jane)
	‘being shouted at by peers’(Leigh)
	‘being timid’(Andy 1st S)
	‘being told to shut up by peers’(Leigh)
	‘being undiagnosed’ with ADHD(Jane)
	‘being undiagnosed’ with anxiety disorder(Jane)
	‘being undiagnosed’ with depression(Andy)
	‘being undiagnosed’ with dyslexia(Jane)
	‘being undiagnosed’ with dyspraxia/DCD(Karen)
	‘being undiagnosed’ with OCD(Leigh)
	‘big social leap’(Mark)
	‘confusion at being put into exclusion’(Jane)
	‘confusion related to peers’ (being different)(Mark)
	‘expressing emotions’(Mark)
	‘feeling different to peers’(Mark, Karen, Leigh)
	‘friendships’(Mark, Karen, Jane, Leigh, Andy)
	‘indirect homophobia’(Mark)
	‘meltdowns’(Karen)
	‘not knowing where to go during break times to avoid bullies and for a quiet space’(Andy)
	‘not wanting to draw attention to self’(Mark, Andy)
	‘peers who didn’t want to learn’(Leigh, Andy)
	‘social difficulties’(Mark, Jane, Leigh, Andy)
	‘social exhaustion’(Jane)

	‘**stigma of having ASC**’(Mark) ‘**teacher’s negative behaviours towards them**’(Jane) ‘**timid**’(Andy) ‘**undiagnosed ASC**’(Mark) (Mark emphasised other difficulties associated with this such as living in a household that did not accept that he could have autism)
Total	*f* = 48
Mental health CS	
	‘**anorexia**’(Jane) ‘**anxiety**’(Jane) ‘**depressive symptoms**’ (Andy 2nd S) ‘**low mood**’(Andy) ‘**sad days**’(Andy 2nd S) ‘**self-harming**’(Jane) ‘**suicide attempts**’(Jane) ‘**trichotillomania**’(Jane) ‘feeling **downtrodden**’(Leigh) ‘feeling **shame**’(Leigh) ‘feeling **sadness**’(Andy)
Total	*f* = 11
Combined CS frequency	
Total	*f* = 88

Table (b)

Secondary CTT: Holistic-form analysis (HFA) correlations, patterns, and relationships amongst participant data

	Mark	Karen	Jane	Leigh	Andy (1st secondary)	Andy (2nd secondary)
(i) Previously identified CS total score	n = -85	n = -55	n = -110	n = - 85	n = - 85	n = - 65
(ii) CFA (nonverbal) total score	n = - 50	n = - 25	n = - 125	n = - 50	n = - 50	
(iii) State of health total score	n = - 100 (MaD)	n = - 100 (MaD)	n = - 100 (MaD)	n = - 100 (MaD)	n = - 100 (MaD)	n = +200(2) (MaI)
HFA total score: Narrative progression or regression	n = - 235 (regressive narrative decline)	n = - 180 (regressive narrative decline)	n = - 335 (regressive narrative decline)	n = - 235 (regressive narrative decline)	n = - 235 (regressive narrative decline)	n = + 135 (progressive narrative growth)

CTT(P) = core transitioning theme (phase), TST = transitioning subtheme, MaD = major deterioration in health, MaI = major improvement in state of health, Ac = Academic, ES = emotional-social, EST - emotional-social transitioning, CSS = concurrent stressor support

Appendix 5.3: Correlations, patterns, and relationships among participants’ data during the sixth form CTT

Table (a)

	Frequency category occurrence of concurrent stressors and concurrent stressor support during the sixth form CTT
EST-CS	
	‘**fear about the long journey she had to make to sixth form**’(Karen) ‘**fear that she would not get along with her sixth form peers**’(Karen) ‘**struggled to readapt to sixth form college**’(Jane)
Total	*f* = 3
Major Ac-CS (impacting state of health)	
	‘**A-Level exams**’(Mark, Leigh) ‘**increase academic demands**’(Jane, Leigh, Andy) ‘**no reasonable adjustment in place for exams due to unwillingness to disclose**’(Mark) ‘**time**’(Leigh, Andy)
Total	*f* = 8
Major ES-CS	
	‘**being undiagnosed ASC**’(Mark, Karen, Andy) ‘**fear about standing out from his peers**’(Andy) ‘**sensory challenges** (SnC)(Jane) ‘**worrying about others**’(Leigh)
Total	*f* = 6
Minor ES-CS	
	‘**ASC diagnosis**’(Jane) ‘**being ignored**’(Andy) ‘**being undiagnosed**’ with depression(Andy) ‘**being undiagnosed**’ with dyspraxia/DCD(Karen) ‘**being undiagnosed**’ with OCD(Leigh) ‘**changes**’(Jane) ‘**expressing emotions**’(Mark) ‘**friendships**’(Jane) ‘**groups**’(Andy) ‘**loneliness**’(Andy) ‘**meltdowns**’(Jane) ‘**people bitching and talking behind her back**’(Jane) ‘**reminiscing**’(Jane) ‘**social difficulties**’(Jane) ‘**social exhaustion**’(Jane) ‘**stigma of having ASC**’(Mark, Jane)
Total	*f* = 17
Mental health CS	
	‘**anorexia**’(Jane) ‘**anxiety**’(Jane) ‘**depressive symptoms**’(Andy) ‘**sadness**’(Andy) ‘**self-harming**’(Jane) ‘**stress**’(Jane)
Total	*f* = 6
Combined CS frequency	
Total	*f* = 40

Table (b)

Sixth form CTT: Holistic-form analysis (HFA) correlations, patterns, and relationships amongst participant data

	Mark	Karen	Jane	Leigh	Andy
(i) Previously identified CS total score	n = -35	n = -20	n = -85	n = - 25	n = - 60
(ii) CFA (nonverbal) total score	-	-	n = +50	-	-
(iii) State of health total score	n = + 100 (MaI)	n = +100 (MaI)	n = +200(2) (Ma I	n = +100 (MaI)	n = +100 (MaI)
HFA total score: Narrative progression or regression	n = + 65 (progressive narrative growth)	n = + 80 (progressive narrative growth)	n = + 165 (progressive narrative growth)	n = + 75 (progressive narrative growth)	n = + 40 (progressive narrative growth)

CTT = core transitioning theme, TST = transitioning subtheme, MiD. = minor deterioration in state of health, Ac = Academic, ES = emotional-social, EST - emotional-social transitioning, CSS = concurrent stressor support

Appendix 5.4: Correlations, patterns, and relationships among participants’ data during the university (BSc) CTT

Table (a)

	Frequency category occurrence of concurrent stressors and concurrent stressor support during the university (BSc) CTT
EST-CS	
	‘fear about moving away from home’(Karen)
	‘fear of being alone’(Andy)
	‘fear of change’(Karen)
	‘feeling homesick’(Karen)
	‘guilt about not getting used to university life as quickly as she thought she should’(Karen)
	‘having to meet a whole load of new people’(Mark)
	‘having to visit other universities with his parents even though he had ‘already decided due to his chosen universities autistic CSS’(Mark)
	‘not being able to tell parents that he wanted to go to his chosen ‘university due to its autistic CSS’(Mark)
	‘social difficulties with peers’(Leigh) (worried would continue)
	‘the uncertainty ahead of him’(Mark)
	‘uncertainty about whether she wanted to go to university or not’(Karen)
	‘whether she had sufficient independent living skills to live alone’(Karen)
	‘worried about being rejected by his peers and that no one would like him’(Mark)
Total	*f* = 13
Major Ac-CS (impacting state of health)	
	‘executive functioning’(Mark, Karen, Jane, Leigh, Andy)
	‘group’(Karen)
	‘increased academic demands’(Karen, Jane, Andy)
	‘math’(Jane)
	‘processing’(Karen)
	‘time’(Karen, Jane, Leigh, Andy)
Total	*f* = 15
Major ES-CS	
	‘being undiagnosed ASC’(Karen, Andy) (Andy was diagnosed during his first year and Karen at the end of her degree).
	‘fear about standing out from his peers’(Andy)
	‘sensory challenges’ (SnC)(Jane)
	‘worrying about others’(Leigh)
Total	*f* = 5
Minor ES-CS	
	‘ASC diagnosis’ (Andy)
	‘being undiagnosed’ with depression (Andy) (Andy was diagnosed in his second year).
	‘being undiagnosed’ with dyspraxia(Karen)
	‘being undiagnosed’ with OCD(Leigh)
	‘changes’(Mark, Karen, Jane)
	‘communication’(Andy)
	‘concern about lecturers treating differently to peers because of ASC diagnosis’(Andy)
	‘difficulties when peers party and drink’ (Andy)
	‘disclosing ASC’(Mark, Andy)
	‘expressing emotions’(Mark)
	‘fear of change’(Jane)
	‘fear of failing’(Mark, Karen)
	‘friendships’(Mark, Karen, Jane, Andy)
	‘groups’(Karen, Andy)
	‘living independently’ (Karen, Jane, Andy)
	‘loneliness’(Jane, Andy)
	‘meltdowns’(Jane)
	‘running out of money by end of term due to overspending’(Andy)
	‘sleep’(Mark)
	‘social difficulties’(Mark, Jane, Andy)
	‘social vulnerability’(Jane)
	‘stigma of having ASC’(Andy)
	‘taking on the responsibility of paying household bills’(Leigh)
	‘trying not to be too weird’(Jane)
	‘uncertainty’(Karen)
Total	*f* = 38

Mental health CS	
	‘anxiety’(Jane)
	‘anxiety about world affairs’(Leigh)
	‘depressive symptoms’(Andy)
	‘emotional-social problems impacting ability to do work’(Andy)
	‘fear about having a mental health condition’(Andy)
	‘fear of academic level and amount of work’(Andy)
	‘fear of being talked down to or treated as if not intelligent’(Andy)
	‘fear that others would interact with him differently because of his autism diagnosis’(Andy)
	‘fear that others would not consider him normal’(Andy)
	‘fear that she couldn’t finish her degree’(Karen)
	‘mood swings’(Andy)
	‘phobias’(Leigh)
	‘sadness’(Andy)
	‘stress’(Karen, Andy)
Total	*f* = 15
Combined CS frequency	
Total	*f* = 85

Table (b)

University (BSc) CTT: Holistic-form analysis (HFA) correlations, patterns, and relationships amongst participant data					
	Mark	Karen	Jane	Leigh	Andy
(i) Previously identified CS total score	n = - 45	n = -40	n = -80	n = - 50	n = - 155
(ii) CFA (nonverbal) total score	n = +50	n = +50	-	n = +50	n = +50
(iii) State of health total score	n = + 100 (MaI)	n = +50 (MiI)	n = +100 (MaI)	n = - 50 (MiD)	n = -100 (MaD)
HFA total score: Narrative progression or regression	n = + 105 (progressive narrative growth)	n = + 60 (progressive narrative growth)	n = + 20 (progressive narrative growth)	n = - 50 (regressive narrative decline)	n = - 205 (regressive narrative decline)

CTT = core transitioning theme, TST = transitioning subtheme, MiD. = minor deterioration in state of health, Ac = Academic, ES = emotional-social, EST - emotional-social transitioning, CSS = concurrent stressor support

Appendix 5.5: Correlations, patterns, and relationships among participants’ data during the university (MSc) CTT

	University (MSc) CTT: Holistic-form analysis (HFA) correlations, patterns, and relationships amongst participant data	
	Karen	Leigh
(i) Previously identified CS total score	-	-
(ii) CFA (nonverbal) total score	-	-
(iii) State of health total score	n = +100 (MaI)	-
HFA total score: Narrative progression or regression	n = + 100 (progressive narrative growth)	n = 0 (stable)

CTT = core transitioning theme, TST = transitioning subtheme, MiD. = minor deterioration in state of health, Ac = Academic, ES = emotional-social, EST - emotional-social transitioning, CSS = concurrent stressor support

Appendix 7.1: Check list for neuro-diverse individual (student) differences & difficulties potentially influencing their ability to adapt to change & transition

Emotional-Social concurrent stressor (CS) check list

Undiagnosed

- ☐ Undiagnosed with a neuro-diverse condition CS (likely to have and/or awaiting an assessment)

Friendship/social CS

- ☐ Friendship CS
- ☐ Social CS
- ☐ Social exhaustion CS
- ☐ Shy/timid CS
- ☐ Psycho-social age less than chronological age resulting in CS
- ☐ Social difficulties worsening with age CS
- ☐ Loneliness CS
- ☐ 'Self' concept difficulties resulting in CS

Mental health CS

- ☐ Anxiety CS
- ☐ Worry CS
- ☐ Self-harming CS
- ☐ Post-Traumatic Stress Disorder (PTSD) CS
- ☐ Eating disorder related CS (e.g., anorexia/Food selectivity)
- ☐ Trichotillomania CS
- ☐ Fears CS (e.g., environmental concerns, animal worries)
- ☐ Phobias (e.g., social phobia, school phobia)
- ☐ Obsessive Compulsive Disorder (OCD) CS
- ☐ Depression (low mood) CS

Bullying/discrimination

- ☐ Loneliness CS
- ☐ Social isolation CS

Other emotional-social CS

- ☐ Abuse from peers/parents CS
- ☐ Being labelled CS (e.g., as a problem child)
- ☐ Groups CS
- ☐ Gastrointestinal problems CS

Academic concurrent stressor (CS) check list

Academic

- ☐ Time CS
- ☐ English language CS
- ☐ Math CS
- ☐ Fine motor skill CS
- ☐ Rigidity CS
- ☐ Groups/social CS
- ☐ Academic jump from one educational phase to the new phase CS
- ☐ Academic pressure to get high grades CS

- Exam techniques and difficulty moving on to the next question CS
- Teachers prioritizing core subjects to detriment of other subjects CS

Executive functioning

- Emotional regulation CS
- Self-control CS
- Perseverance CS
- Flexibility CS
- Organisation CS
- Processing CS
- Attention, concentration, distractibility CS
- Problem-solving CS
- Time management (concept of time) CS
- Working memory CS
- Planning & prioritising CS
- Task initiation CS
- Goal-directed behaviour CS
- Self-monitoring CS
- Central coherence CS
- Dropping out of educational phase or not going to school CS

Autism, self and others concurrent stressor checklist

- ***Disclosing & asking for support CS***
- ***Co-occurring CS***
    - Attention Deficit Hyperactive Disorder (ADHD) CS
    - Dyspraxia/Developmental Coordination Disorder (DCD) CS
    - Dyslexia CS
    - Dyscalculia CS
    - Restrictive Repetitive Behaviours (RRB) CS
    - PICA CS
    - Echolalia CS
    - Sensory CS
    - Sleep CS
    - Epilepsy CS
    - Psychosis CS
- ***Negative educational transitioning experiences of due to being undiagnosed with autism CS***
- ***Negative experiences of seeking a diagnosis for autism CS***

Transitioning between educational phases

Anxiety/fear

- anxiety about so much change CS
- anxiety about what to expect in new school CS
- being forced to have a shower during PE CS
- changing schools being nerve wrecking CS
- fear about the academic jump CS
- fear about the long journey to new educational phase CS
- struggle to readapt to new educational phase CS
- fear about moving away from home CS

- ☐ fear of being alone CS
- ☐ fear of change CS
- ☐ feeling homesick CS
- ☐ guilt about not getting used to university life as quickly as they thought they should CS
- ☐ having to visit other universities with his parents even though they had ‘already decided due to the chosen universities autistic CSS resulting in CS
- ☐ not being able to tell parents that they wanted to go to the chosen university due to its autistic CSS resulting in CS

Social

- ☐ apprehensive due to the social upheaval CS
- ☐ fear of being bullied in new school CS
- ☐ lack of explicit instructions on how to interact and communicate with peers CS
- ☐ fear that they would not get along with their new peers CS
- ☐ having to meet a whole load of new people CS
- ☐ social difficulties with peers CS
- ☐ worried about being rejected by their peers and that no one would like them CS

Sensory concurrent stressor (CS) check list

Sensory

- ☐ Sight CS
- ☐ Sound CS
- ☐ Smell CS
- ☐ Taste CS
- ☐ Touch & texture CS
- ☐ Proprioceptive system CS
- ☐ Vestibular system CS
- ☐ Interoceptive system CS

☐ **Change & uncertainty CS**

☐ **Independence CS**

☐ **Communication CS**

Appendix 7.2: Educational Transitions. A guide to best practice: Supporting neuro-diverse students' transitions into a new educational phase and with their day-to-day needs (Intended for persons supporting neuro-diverse students)

Table of Contents

- Social skills

Independence differences & difficulties

- Academic independence
- Emotional-social skills
- Day-to-day living skills
- Day-to-day health skills

Mental health differences and difficulties

- Anxiety
- Depression
- Eating disorders
- Fears/Phobia
- Obsessions, Rituals, Routines
- Obsessive compulsive disorder (OCD)
- Post-traumatic stress disorder (PTSD)
- Self-harming
- Suicidal ideation
- Worries

Sensory differences & difficulties

- Sight
- Sound
- Smell
- Taste
- Touch & texture
- Proprioceptive system
- Vestibular system
- Interoceptive system

Primary school

- Supporting the transition into Primary school
- Support available at Primary school
  - *The importance of disclosing & asking for support*
  - *What a neuro-diverse student is entitled to because of their condition(s)*
- Ongoing day-to-day support needs in Primary school
  - *Academic & executive functioning differences & difficulties*
  - *Behavioural differences & difficulties*
  - *Change & Transition differences & difficulties*
  - *Communication differences & difficulties*
  - *Emotional-social differences and difficulties*
  - *Independence differences & difficulties*
  - *Mental health differences and difficulties*
  - *Sensory differences & difficulties*

Secondary school

- Supporting the transition into Secondary school
- Support available at Secondary school
  - *The importance of disclosing & asking for support*
  - *What a neuro-diverse student is entitled to because of their condition(s)*
- Ongoing day-to-day support needs in Secondary school
  - *Academic & executive functioning differences & difficulties*
  - *Behavioural differences & difficulties*
  - *Change & Transition differences & difficulties*
  - *Communication differences & difficulties*
  - *Emotional-social differences and difficulties*
  - *Independence differences & difficulties*
  - *Mental health differences and difficulties*

Appendix 7.3: Preparing for secondary school or sixth form: Managing your transition into a new educational phase and your day-to-day needs (Intended for neuro-diverse students)

Appendix 7.4: Preparing for university: Managing your transition into university and your day-to-day needs (Intended for neuro-diverse students)

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