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## TOURISM AND AUTISM: JOURNEYS OF MIXED EMOTIONS

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# **TOURISM AND AUTISM: JOURNEYS OF MIXED EMOTIONS**

## **ABSTRACT**

There is an evolving tourism literature around psychological wellbeing, social exclusion and disability. This paper advances tourism knowledge into the terrain of psychological health and developmental complexities, and psychological distress. It draws on a phenomenological position to understand the lived experiences of mothers of children with developmental difficulties, in this case diagnosed with autism spectrum disorder (ASD). It discusses the emotional and everyday challenges of caring for a child diagnosed with ASD on holiday, discusses the perceived benefits holidays offer and outlines care-giving strategies adopted by mothers to manage their children's tourism experiences. The paper discusses the uniqueness of the context of autism and problematizes popular discourses, which predominantly frame tourism as pleasurable settings of escape, stimulation, novelty and relaxation.

Key words: disability; care-giving; mothers; children; well-being; mental health.

## 1. INTRODUCTION

Wellbeing is a multidimensional concept, which has recently been considered in tourism contexts (McCabe & Johnson, 2013; Petrick & Heuther, 2013), where scholars have particularly examined later-life wellbeing (e.g. Morgan, Pritchard & Sedgley, 2015) and quality of life (e.g. Dolnicar, Yanamandram & Cliff, 2012). The past decade has seen an increase in tourism research adopting concepts from the physical and psychological sciences; indeed, positive psychology has been so well received that its advocates advise tourism educators, practitioners and researchers “...that holidays make people happy” (Filep 2012, p.38). This focus on the positivity of tourism has also seen research engaged with marginalisation, deprivation and social exclusion highlight how tourism benefits socially marginalised groups by elevating self-worth and extending social worlds and social interaction (McCabe, 2009). Whilst we recognise the value of such research, positive psychology has been criticised for overlooking the embodied, relational and complex manifestation of emotions and offering a simplified, individualised understanding of subjectivity (Greco & Stenner, 2013). Therefore, we seek to explore the ways in which tourism experiences, specifically those involving children with disabilities, are a messy, conflicting constellation of emotions, embracing stress and guilt as well as pleasure and excitement (Backer & Schänzel, 2012). Tourism studies has rarely considered negative emotions and then largely in service settings (Liu, 2016). Instead its overwhelming focus has been on positive emotional stimulation, perhaps because it has traditionally been framed as a hedonic experience (Hosany, 2012; Picard & Robinson, 2012).

A growing cadre of tourism scholars address physical (e.g. Buhalis & Darcy, 2011) and sensory impairment (e.g. Richards, Pritchard & Morgan, 2010; Yau, McKercher & Packer, 2004) whilst a number focus on social exclusion (e.g. Minnaert, 2014). Our paper extends tourism’s reach into psychological distress and psychological health and developmental complexities, connecting with established work in leisure studies and community psychology (e.g. Walker, Hart & Hanna, 2017). It draws on a phenomenological position to explore the emotional care-giving experiences of mothers holidaying with a child diagnosed with Autism Spectrum

Disorder (ASD), a neglected area of research in both disability and tourism studies (Mactavish, MacKay, Iwasaki & Betteridge, 2007). The paper is grounded in mental health and psychology research approaches (Gilbert, Rose & Slade, 2008), which value highly personalised testimonies of the affective, embodied, experiential, individual and intersubjective experiences of those living with, and caring for, individuals with mental health issues and developmental difficulties (Aumann & Hart, 2009).

## **2. LITERATURE REVIEW**

There is a growing corpus of tourism research exploring the experiences of people with disabilities, extensively reviewed elsewhere (e.g. Buhalis & Darcy, 2011) in the book-length format that such an undertaking requires. There is less focusing on children with disabilities (Kim & Lehto, 2013) and almost none on family care-givers for individuals with intellectual, cognitive and learning disabilities and mental health conditions (Nind & Seale, 2009); an exception being the Mactavish et al. (2007) study. In contrast, there is a body of leisure studies scholarship examining both the experiences of individuals with psychological disabilities and their carers (e.g. Dodd, Zabriskie, Widmer & Eggett, 2009). Research has explored the impacts of community arts projects and support centres (Aumann & Hart, 2009) and activities such as fishing, cycling and singing on the wellbeing of individuals diagnosed with a range of learning and behavioural difficulties and mental health conditions (Walker et al. 2017). Some of these studies have focused on individuals diagnosed with ASD to examine the links between leisure participation, stress and quality of life (e.g. García-Villamizar & Dattilo, 2010) and to determine how these people process sensory information during leisure activities (Hochhauser & Engel-Yeger, 2010). Further studies have investigated the barriers to leisure for children diagnosed with ASD/attention deficit hyperactivity disorder (e.g. Emira & Thompson, 2011) and the challenges faced by parents seeking to engage them in leisure (e.g. McGinnis, Fullerton & Rake, 2014).

Notwithstanding such research, little enquiry examines the experiences of parents holidaying with children diagnosed with learning and behavioural

difficulties; this despite the importance of the family in determining the tourism and leisure opportunities of children with disabilities (Brewster & Coleyshaw, 2010). Indeed, the predominance of children in the practice of tourism contrasts with their neglect in its study (Poria & Timothy, 2014; Schänzel, Yeoman, & Backer, 2012). Research that has focused on holidays for children diagnosed with ASD and their families has examined local government provision and identified its role in reducing stress and maintaining family cohesion (Chan & Sigafos, 2001; Gray, 1994; Olsson & Hwang, 2001; Tarleton & Macaulay, 2003). Similar studies in the third sector demonstrate how holidays create spaces for children with disabilities and their families to enhance their relationships, wellbeing and resilience (Every Child Matters, 2010). This echoes research, which regards family holidays as opportunities to escape, relax, and enjoy shared experiences (Prentice, 2004; Yoo, McIntosh & Cockburn-Wooten, 2016; Zabriskie & McCormick, 2003). Indeed Dodd et al. (2009, p.262) observe that researchers have consistently found “positive relationships between family leisure involvement and family functioning.”

This is a nascent area of tourism research with pioneering studies recognising tourism’s role in enhancing physical and mental health and quality of life and reinvigorating relationships for families with a child with a disability (Kim & Lehto, 2013). Whilst some researchers maintain that families with and without a child with a disability participate in leisure in the same way (Ferguson, 2002), others emphasize its value for families with a child with a disability (Scholl et al., 2003). However, evidence from developmental disability research also suggests that holidays can have a negative impact on family functioning for families with a member diagnosed with ASD (Abbeduto et al., 2004; Ghaziuddin & Greden, 1998). Parents in these families often experience higher levels of tension and anxiety than those of children with other disabling conditions (Gray, 1994; Williams & Aaker 2002), because of coping with difficult behaviours and providing high levels of emotional support and supervision.

Advancing from this research bridgehead, we turn attention to the emotional and commonplace tourism experiences of mothers holidaying with a child diagnosed with ASD. To do this however, we need to contextualise recent understandings of ASD and its diagnosis within contemporary mental health research. This cannot be a

comprehensive conceptualisation of ASD; rather we aim to offer a sense of the lived experiences of mothers holidaying with children diagnosed with ASD and the subsequent complexities this presents in the tourism context. ASDs have largely been characterised by a range of difficulties in social interaction, communication, restricted interests/fluctuating attention span, and a propensity for repetitive behaviours (American Psychiatric Association, 2000). These characteristics were previously understood as a range of diagnoses (Asperger's Disorder, Autism etc.) under the umbrella term of 'Pervasive Developmental Disorders.' However, the most recent iteration of the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013) now categorises all such mental health issues, including conditions such as Asperger's Disorder, in the broader diagnosis of ASD (with Rett Disorder the only diagnosis remaining an independent diagnosis). It should be noted that whilst there are distinct differences in approaches towards mental health and disability between the UK and USA, the DSM has long been the standard diagnostic manual used by UK health professionals for mental disorder diagnoses.

As with all mental health issues in the DSM, there is some resistance to pathologising 'behaviours' and 'symptoms' into mental illness. For example, the categorisation and treatment of thoughts and behaviours through a mental health discourse has been problematized since the anti-psychiatry movement and the publication of Szasz's (1974) and Foucault's (1988) seminal works. As Predescu and Sipos (2013, p.11) note in their study of the quality-of-life of mothers of children diagnosed with ASD, the condition can best be understood as a subjective and objective multi-dimensional concept that is "...influenced by personal and environmental factors... and is improved by self-determination, resources, purpose in life and sense of belonging." Such understandings of mental 'health' and mental 'illness' as more than a series of diagnosis criteria has also been explored by scholars examining the social nature of psychological distress (e.g. Walker et al., 2015). Notwithstanding such dispute, most researchers concur that for those living in a world increasingly predicated on a fixed set of 'norms', individuals falling outside of these often have very distressing lives (Cromby, Harper & Reavey, 2013). In view of

these tensions, we use the term 'diagnosed with ASD' to avoid enforcing an attempt at objectively classifying a complex mental health issue that is both multifaceted and contested.

Individuals diagnosed with ASD frequently find social interaction, imagination and communication problematic, whilst many struggle to understand implicit social norms and find negotiating others' emotions and interpersonal relationships challenging (Aston, 2012). Some individuals cannot cope with change and engage with repetitive or familiar behaviours, and can also experience distress when they feel excessively stimulated (Bellini, 2004). It is not unexpected that people diagnosed with ASD describe their world as a mass of people, places and happenings, with which they struggle to cope (The National Autistic Society, 2016). Equally unsurprisingly, individuals diagnosed with ASD have an increased likelihood of experiencing depression, anxiety and social isolation (Orsmond et al., 2013; Sterling et al., 2015), compounded by the social discrimination of being labelled as having a 'mental illness,' and a discourse of disability (Cromby et al., 2013; Runswick-Cole, 2008).

Given this discussion, we do not offer a definitive definition, pathology or conceptualisation of ASD but underline that the diagnosis has an impact on the life of the individual diagnosed and those around them. Tourism can enable us to alter our daily life rhythms and experience emotionally-heightened interactions (Picard, 2012). Yet, whilst the 'holiday' is socially constructed as a space for relaxation, in which to enjoy family time and new experiences, primary carers of children diagnosed with ASD are faced with a range of practical and emotional challenges whilst away from the routine of home (Meirsschaut, Roeyers & Warreyn, 2010). The clear majority of these primary carers are mothers, themselves more likely to be at risk of serious psychological stress than parents of children with other developmental disabilities or parents of non-disabled children (Bromley et al., 2005). Research with parents of young children suggests that women engage in more emotional labour - gendered emotional work that has "psychological health consequences" (Strazdins & Broom 2004, p.356). Here we draw on Dieffendorff, Croyle & Gosserand's (2005) understanding of 'emotional labour' as the management and suppression of feelings/emotions. Such management and suppression of feelings is suggested to



have profound psychological consequences for women endeavouring to be ‘good mothers’ (Lutz, 2001) and it is to the stories of six such mothers that we now turn.

### **3. METHODS**

The study draws on a phenomenological position to uncover the affective, relational, embodied and unique lived experiences/life worlds (Habermas, 1987) of mothers holidaying with a child diagnosed with ASD. As a theoretical position phenomenology is particularly suited to the study of emotional engagement in tourism (Picard, 2012) and to exploring the ways in which people experience their reality, their engagement with objects and people and ultimately the meanings these hold (Eatough & Smith, 2007). In contrast to approaches that attempt to generalise people’s thoughts and feelings, this enables us to explore the nuances of an individual’s ‘lifeworld’. We make no attempt to suggest that our findings are ‘representative’, ‘generalizable’ or without interpretation by the research team. Whilst critics may see this as a weakness in our approach, we present this project within the tradition of methodologically sophisticated qualitative research, which celebrates rather than hides such issues (Parker, 2004). Further, phenomenology offers a distinct set of features which are often missing in alternative qualitative approaches, including: temporality (experience of time); spatiality (experience of space); embodiment (experience of one’s own body); intersubjectivity (experience of relationships with other people); and selfhood (experience of the self) (Ashworth, 2003).

From this perspective, we utilised the psychological methodology of Interpretative Phenomenological Analysis (Smith, Flowers & Osborn, 1997), previously used to investigate for example, experiences of people with mental health issues engaging in community arts projects (Lawson, et al., 2013) and parental experiences of childhood cancer (Schweitzer et al., 2012). This methodological approach affords attention to the lived experience of the individuals, including their feelings, emotions, and their understanding of behaviours. It addresses the “...web of thought-infused feelings and feeling-infused thoughts experienced by an individual as she creates her own psychic life within a set of interpersonal and cultural relations” (Chodorow 1999, p.166). Whilst phenomenology and IPA have been used in tourism

research, it has been argued that “...past attempts have inadequately addressed the theoretical and philosophical assumptions that influence a researcher’s approach and interpretations” (Pernecky & Jamal, 2010, p.1055); we hope to have gone some way to addressing this critique.

Our relationship with Cerebra, a UK third sector organisation and registered charity, which supports over 11,000 parents to improve the lives of children with brain injury and brain-related neurological conditions (<http://www.cerebra.org.uk>) was central to our approach. Cerebra provides advice, grants and support services and operates its own holiday home. The organisation approached us to investigate the holiday experiences of its members who have children diagnosed with ASD. Such collaborations between academics and third sector organisations enable the latter to benefit from academic research skills and credibility and ensure the priorities of people with disabilities and their organizations are involved in shaping research (Priestley, Waddington & Bessozi, 2010). This form of collaboration can also facilitate knowledge-sharing amongst people with disabilities, service providers and policymakers, creating “action and politically led” research (Macbeth, 2010, p.483).

Cerebra’s Children’s Coordinator emailed its members with children diagnosed with ASD resident within an hour’s drive of the research team’s university. This was a decision taken for logistical reasons as we did not want to disturb the home routines of the mothers’ children and yet wanted to conduct the interviews in person due to their sensitivity and our desire to conduct them with warmth and empathy (Sieber & Tolich 2013). Due to UK data protection, Cerebra was unable to share any members’ contact details until they agreed to participate in the research. Six of the women who volunteered to take part in the study were then contacted by the researchers to arrange an initial meeting. Whilst six participants may appear a small number in positivist-influenced qualitative research, in Interpretative Phenomenological Analysis rich material emerges from a small number of interviews to provide clarity on an under-served subject (Gray, 2003). There has long been debate over the optimum sample size for IPA research, with notable projects ranging from one (Eatough & Smith, 2006) to a large IPA sample size of 14 participants (Pridgeon & Grogan, 2012). We take our lead from Reid et al. (2005) and Smith et al.

(2009) who argue that the more participants included in IPA, the more there is a diffusion of their individual lived experiences, and a reduction of the interpretations of their unique life worlds, the essential characteristics of IPA.

To offer some context on the participating women, four have two or more children and two have one child, with the age ranges of the child diagnosed with ASD ranging from nine to 19. All are heterosexual, white women; two are married, three divorced and one widowed. All are the primary carers for their children; three are full-time carers and three work part-time (table 1). These are typical employment patterns, as only 11% of UK parents of children diagnosed with ASD work full-time, due to the demands of the condition (Ambitious About Autism, 2016). Whilst we acknowledge that these factors will have an impact on the ways in which the participants are empowered/disempowered to live their lives, we are in no way attempting to offer demographic details to suggest any causal relationships or broader sociological observations. Rather we are positioning this research within the phenomenological and psychology arena and offer this information for the reader to obtain a sense of the interviewees.

Table 1: Study Participants here

The research project was approved by the main contact's university ethics committee and the research team were guided by the four overriding principles of ethical research: do no harm, do positive good, show respect for people's autonomy and treat people fairly (Gilhooly, 2002). Each mother was given an information and consent form explaining: the research purpose; how their words might be used; that participation was voluntary and anonymous. However, following ethical principles alone will not necessarily ensure ethically sound research and individual researchers must adopt a relational ethics approach to make situation-specific decisions based on their ethical engagement and personal responsiveness with their study participants (González & Iffland, 2014). As experienced qualitative researchers, we continually assessed the participants' wellbeing during the interviews. Moreover, as we were aware that some discussions might be distressing, we acknowledged the limitations

of our roles as researchers and ensured that Cerebra would offer support should the need arise.

All interviews lasted 60 to 90 minutes and were held either in the women's homes or at the university; all were audio-recorded and transcribed. Each interview was framed by Sieber and Tolich's (2013, p.40) advice that "the warmth of empathy and human kindness has a vital role in making us ethical researchers" and opened with a broad discussion of the participants' holiday activities. Thereafter the women 'drove' an open conversation, providing insight into the fine-grained nuances of meaning that constitute their holiday experiences (Ray, 2007). Whilst we had no interview checklist, the conversations typically covered the frequency and type of their holiday taking, the destinations visited, their booking processes and holiday motivations, the positive and negative aspects of their experiences, the practical and emotional aspects of holidaying and sensitivities of care-giving. The interviews were then transcribed and analysed through multiple readings to fully immerse us in the data and the participants' stories (Smith & Osborn, 2003). Following this, the team met to discuss our independent readings of the data and assembled a consensus coding of the transcripts. Whilst we sought to preserve the uniqueness of each participant, we identified commonalities and interconnections across the interviews around the interpersonal, affective and embodied experiences of the mothers (table 2).

As with all good qualitative research, we acknowledge that alternative readings of the data, and alternative foci of the analysis, could have been offered at this and subsequent stages (Willig, 2013). In the spirit of transparent, reflexive research, we should highlight that the four researchers are able-bodied parents with personal experience of caring for or working with children requiring additional support, their families and community organisations. Therefore, this element of our subjectivities' will undoubtedly have influenced our reading of our participants' voices, a feature of IPA and qualitative research in general (Ashworth, 2003). The final analysis stage then examined the rich description and conceptual interpretations to reveal the life worlds of these individuals and their experiences when on holiday with their children (Smith & Osborn, 2003). In line with our phenomenological position

that pays attention to the unique, affective, embodied and interpersonal experiences of our participants, we quote from their anonymised narratives at length in the next section.

#### **4. JOURNEYS OF MIXED EMOTIONS**

This section of the paper presents and discusses the interviews with the six mothers of children diagnosed with ASDs. The four commonalities and interconnections that emerged from our conversations with them (table 2) form sub-sections, which are presented and discussed in turn.

Table 2: Visual representation of the thematic spread for each interview here

##### **4.1. “As long as everything goes according to plan”**

Tourism is typically defined in opposition to home and work and as an opportunity for heightened emotional encounters, pleasure and escape from routine (Picard, 2012; Prentice, 2004). It is also frequently characterised as offering transformative experiences (Reisinger, 2013); thus Fullagar’s (2011) exploration of travel and psychological distress suggests that tourism presents women with openings to renegotiate their sense of self. Such interpretations only partially align with the experiences of the women in our study. For them, holidays are desirable spaces of family relaxation yet they simultaneously create enormous pressures as the predictability of the everyday is something to appreciate; they are times of pleasure and yet are riven with anxiety, guilt and stress (Williams & Aaker, 2002). Spontaneity, surprise and cultural immersion are not found in these women’s tourism lexicons; instead their language is one of repetition, comfort and familiarity.

Tourism research exploring disability highlights how navigating unfamiliar tourism environments requires significant planning for people with disabilities (Richards et al., 2010), a challenge magnified for families with a child diagnosed with ASD as home life for these families is highly routinized (Meirsschaut et al., 2010). Each mother emphasised the importance of predictability for her child, such as watching the same DVD, playing the same computer games, wearing the same clothes and

eating the same food. Claire pronounced herself “*the Queen of lists*” whilst Rachel draws up John’s programme: “*Because he can read I do a written schedule for him. He says, ‘Read it to me’... He knows his schedule off by heart. I say, ‘Today is Friday we are going out with’ whoever... he will reel it all off as he has got it so ingrained.*” Lucy spoke of how the lived experience of taking a holiday relates to the routines of home and everyday life, which continue during a holiday. Thus, she explained how Joe habitually refuses to eat his evening meal in the house, meaning her family has eaten out every night for eight years, clouding the association between leisure activities, escape and relaxation and everyday routine. This causes her enormous guilt, as it infringes Western notions of family mealtimes as cultural sites for the socialization of children and falls short of the ideal of ‘happy’ families sitting around the home dining table (Ochs & Shohet, 2006). Instead, their family experience is a rejection of the home environment:

*Food is difficult because he has got this – which sounds terrible I know but we have gone along with it over the years, not that we haven’t tried to fight it – he has this rule of eating out every night, so we have to eat out every night and this has been since he was about 11.*

Whereas for many families, an attraction of a holiday is the opportunity for spontaneity, for children diagnosed with ASDs, this can cause extreme distress. In order to mitigate this, their mothers spend weeks planning every aspect of holidays: the destination; the journey; the type and layout of accommodation; meal arrangements and daily activities. This information is then used to prepare the child prior to the holiday. Claire uses day-trips to “*identify the kind of places that Sean likes being in... and so you know if you spend like a week in that place... it’s not going to be a total disaster.*” Such ‘coping strategies’ are typically employed by parents of children diagnosed with ASD (Meirsschaut et al., 2010) as the need for routine causes them huge emotional and physical stress. As Leanne, Owen’s mother explained:

*You can't spring days on him, you can't say 'right let's get in the car - we are going here.' We have to say three or four weeks in advance, this is the date we are going here, you have to build him up for it... We talk about it, we plan maps of where we are going.*

Claire also discussed such advance preparations:

*It's planned down to what they [Sean & Lauren] are going to eat you know. I mean we will go through the brochures of wherever we are going or you know the town, the tourist information of wherever we are going and down to exactly what meals they are going to have, where they are going to have them, what time you are going to have them... It tends to be a lot of time spent on the internet before you travel.*

Such groundwork requires hours of online and offline research to provide as much clarity as possible for the child. Such research is made more challenging by the tourism industry's failure to fully empower individuals to make informed decisions according to their abilities, requirements and preferences (Buhalis & Michopouloub, 2011), particularly those with cognitive impairments (Hamed, 2013). Recent research (Smith, Amorim & Umbelino, 2013) concluded that, whilst most major airline carrier websites provide information on mobility (90%) and vision (71%) services for disabled passengers, only 41% provide information on services for those with cognitive impairments. In addition to psychologically preparing their children for the holiday, the women expend considerable effort ensuring that they are surrounded by familiar possessions whilst away from home. Unlike more familiar conceptualisations of tourism, they are particularly challenged to create order and routine in unfamiliar environments:

*You have to take a TV with a DVD player obviously, but he also has a personal DVD player, so he's got that. He has got his iPod so he takes that and he's got the chargers for it. He'll take his laptop if he can, even though he doesn't have*

*internet for it but he can play games. He'll take his PSP, he'll take all his gadgets, he's got to have them (Leanne).*

For these families, the unpredictability of holidays is their greatest trial, challenging not only their own encounters but the discourse of spontaneity, which is a dominant meta-narrative in tourism stories (Frolilick, 2013). Charlotte and Lucy revealed the impact of unplanned events:

*As long as everything goes according to plan and everything happens as Rory expects it's ok... but if it doesn't go to plan he can be quite destructive or lash out at people, throw his wellies off, you know that sort of thing. Things like... that can sometimes set him off, really upset him and then anything that might happen that he wasn't expecting like if he was expecting to have something to eat at a particular time or if he expected to have chips at the beach, you know that sort of thing (Charlotte).*

*There is no spontaneity, I mean, I can remember when [Joe] was younger him not even letting us buy ice cream, and you have got other small children with you and you're on holiday – it was because it wasn't planned. If we said we are going to go out to buy an ice cream, maybe that would have been alright but we just happened to be wandering around and thought 'oh those ice creams look nice, let's buy one' – an impromptu sort of thing – he said 'no, no, no, no' (Lucy).*

#### **4.2. “It's just too much”**

Tourism is a constellation of multi-sensory embodied experiences (Pritchard & Morgan, 2010). As tourists, we become 'sensory filters,' processing new environmental information and creating sensory interrelationships between body, mind and environment (Middleton, 2001). Whilst many tourists embrace new foods, smells and sights, for children diagnosed with ASD this is extremely challenging as a common trait of ASD is either intensified (hypersensitive) or under-intensified (hypo-sensitive) sensitivity to sights, sounds, smells, touch and tastes (Bellini, 2004).



Instead of seeking new sensory experiences, their families manage, minimise and remove new environmental information on holiday. This might suggest a desensitising of place and experience but this interpretation is insufficiently nuanced since some destinations offer highly rewarding sensory experiences, although several children did find a change in culture, language, food and built and natural environment just too overwhelming. *“We went to Spain, never again... we had complete meltdowns while we were there. Lauren ended up living on chips and Sean on mashed potato that we had to cook everyday... it was like, this is ridiculous. When you are in a foreign country it gets ten times harder than anywhere else”* (Claire). Similarly, Lucy described a trip to France:

*I can remember... just pulling up at the first town in Normandy – Joe couldn’t cope that it was a different type of building. We went to Brittany one year and it was beautiful, beautiful weather as well, but we weren’t allowed to set foot on a beach the whole holiday because he wouldn’t let us and he’s actually not really set foot on sand since, even now. We have also driven around Amsterdam because he wouldn’t let us set foot in Amsterdam, we just drove around. We have got lots of stories like that. It’s very frustrating going somewhere nice and not being able to actually see it, you know.*

Many parents also talked of their child’s sensitivity to noises and crowds: *“theme parks are no good.... If you try and do the big complicated stuff, the likes of the Disney World and Alton Towers... there is too much stimulation* (Claire). Hotels and restaurants were especially problematic environments:

*Lots of noises, lots of people, big places, too much input, too much audio or visual input really. Going into places that have got a lot of structure like a restaurant that’s, you know, got certain standards and so on, it’s just too much, you know. Having to sit quietly is really difficult* (Lucy).

As a result, most parents preferred peaceful holiday destinations: *“We tend to go out-of-season because it’s not busy then. Owen can’t cope with the hustle and bustle if there are too many people there, he doesn’t like crowds (Leanne). A caravan also meant a familiar environment: “he knows the layout... and when we go, it’s familiarity, he doesn’t like change (Leanne). Holiday resorts are an attractive option for some parents. Lucy explained how Centre Parcs offer a predictable, controlled, crowd-free environment: “because [Joe] knew exactly what the layout was like, he knew where the pool was, where you can go to eat... it worked fairly well because it’s a structured world – it’s not like going abroad when it’s a big huge unknown.” Claire similarly described how the design and entertainment of Haven Holiday Centres made it easier to prepare Sean:*

*they are really good with providing information on exactly what is there, exactly how far away everything is and exactly what you can do... and you know should... you need to access the doctor or the dentist... you’ve got the phone numbers ready there as soon as you arrive.*

The need for tranquillity make airports and aeroplanes highly challenging environments for these children, not only as noisy and frenetic places, but also as sites of surveillance, which require well-ordered behaviour (Morgan & Pritchard, 2005). Some mothers described how heightened airport security made them more anxious about travelling by plane:

*Yes, I would be worried about the security, especially going to America.... Security is so much tighter today isn’t it, somebody behaves a little bit oddly... it’s that security side of it, or if there was a delay whether [Joe] could cope with that (Lucy).*

Others spoke of the stress caused by delays and long flights:

*I was terrified... because I didn't know how [John] was going to react and he was going through a very anxious patch. I did actually speak to my GP who gave me some... not Diazepam, it was one of the 'pams, so I gave him some of that and he was quite sleepy going. But coming back I did explain he had special needs but then they got it all wrong, instead of putting him on first they put him on last and he was absolutely having a meltdown for about half an hour, and I had already given him the tranquilizers (Rachel).*

#### **4.3. “Feeling guilty but trying to have a happy holiday”**

Perhaps one of the greatest trials which the families of children diagnosed with ASD encounter on holiday is prejudice: ‘the gaze of discipline and surveillance,’ which marginalizes many people with disabilities (Eichhorn et al., 2013, p.588). People diagnosed with ASD face intolerance and discrimination because the condition is so misunderstood (National Autistic Society 2016). Indeed, whilst the public verbalizes positive attitudes towards people with disabilities, their non-verbalized feelings are often negative ones of mistrust and opprobrium (Bizjak, Knezevic & Cvetreznik, 2011; Richards et al., 2010). The problem is particularly acute for those suffering from hidden psychological conditions, and reveals the ‘genuine problems and challenges, which... attach to... bodies/psyches that are different from mainstream “norms” (Butler & Parr, 1999, p.2). Mothers of such children work hard to manage their own, their children’s and others’ emotions, suppressing their own emotions and internalising the disapproval others, “including strangers who tried (and often failed) to mask their feelings about disabled children” (Runswick-Cole, 2008, p.117). As Lucy said, her greatest concern on holiday was “*judgemental people.*” Rachel explained:

*If the children get sensory overload, they will create a disturbance, not of their own volition. It is just the way they are dealing with the situation. But it means that you do get a lot of funny looks. You can get comments. I have seen nose to nose discussions between a parent and a member of the public, the member of the public challenging the mum saying ‘your child shouldn’t be playing in that area.’*

People are expected to conform to certain behavioural rules in public. Children diagnosed with ASD are frequently unaware of these social norms and transgression creates a strain on their parents' emotional wellbeing as they face public censure and condemnation (Olsson & Hwang, 2001). Conceptualisations of emotional labour as the management and suppression of feeling (Dieffendorff, Croyle, & Gosserand, 2005) aptly describe the stress of parenting:

*I found other people's responses difficult... when [Joe] was little other people would... think 'oh, he's cute', and... then he would do something outrageous and it was 'oh, my God, why can't you control him?' And so then we would feel bad, we would feel guilty and so it was a non-stop rollercoaster really of feeling bad, feeling guilty but trying to have a happy holiday time and being exhausted as well (Lucy).*

*When [Rory] was say 5 or 6, he was slightly too big to be having a toddler tantrum and I used to think that people were looking at me thinking 'what's she doing, why can't she handle that big child' and I carry him a lot 'cause he's not very strong and so I think that other people think 'why is she carrying that huge monster' (Charlotte).*

As a result of such public disapproval, the mothers enjoy holidays with friends and family as a safe and supportive environment for both them and their children. As Lucy commented: "if Joe's having a meltdown nobody bothers... you're not frowned upon." These trips alleviated the families' isolation on holiday and provided both the mothers and siblings of children diagnosed with ASD with social opportunities:

*Friends who've got children and who've got enough space and a lot of awareness about what Rory needs... somewhere where he feels safe where it doesn't really matter if something goes wrong, who are understanding people (Charlotte).*

*I went with my sister and her son.... They get on really well and they have fun and they are on the beach and it is just much more fun for her [my daughter]. And I have got my sister for company as well and it is just more fun all round. And I just think if it was just the three of us of course we would enjoy it but it is just more fun... going with other people... I have organised a couple of youth hostelling weekends, which has only been one night away but... it has just been fantastic because you take the kids out for long walks and then there is... about 17 families in the hostel. It is just great (Rachel).*

#### **4.4. “A holiday is never relaxed”**

Some studies suggest that the families of children with developmental difficulties find that the required planning and lack of spontaneity makes going on holiday or simply going shopping or out for dinner unappealing (Lerner-Baron, 2007; Mactavish et al., 2007) or even impossible (Myers, Mackintosh & Goin-Kochel, 2009). Leanne explained that if a restaurant does not get Owen’s food order exact, he can ‘explode:’

*You order ‘a burger and chips’, that’s what he wants but it will come out with lettuce on it, and you’ve already said plain. To him that’s the end of the road. You have to keep stipulating it’s got to be plain, it’s got to be plain ...it can be hard, especially if the restaurant is busy.*

Holidays are certainly demanding: “you’re always a bit on edge; you’re never completely relaxed” said Leanne, whilst Rachel commented that:

*I think holidays can be difficult for him because it is a break from his routine, although he will go on holiday but I think obviously it does cause him a certain amount of stress and anxiety... A holiday is never relaxed 100%... he is not at home with all his stuff. And if I am honest I always do prefer being at home with John really.*

It is typical for parents of a child with developmental difficulties to feel guilty about the time and attention they invest in that child (Kim & Lehto, 2013; Meirsschaut et al., 2010) at the expense of their other children's needs (Dodd et al., 2009; Myers et al., 2009). Some mothers resolve this by taking their children on separate holidays, although this increases costs and requires the assistance of another carer. Lucy said: *"last year we did take [Joe] for a week on his own because... the better thing to do is to just focus on him for the week. I think the problem is when it's with two more normal kind of kids with their normal wants and desires and his very rigid way of thinking is just too much.* Whilst Claire commented: *"I took Sean by himself. Not the two of them together. The competing needs are too much, you need to make sure that there is one on one with Sean and then there is someone that has to kind of manage what Lauren does."*

Despite the undoubted challenges, however, all six families had taken a holiday in the last three years; two had travelled extensively in Europe, North Africa and the Americas, although others found it simpler (and perhaps cheaper) to holiday in the UK. As Lucy commented: *"I'm coming round to thinking that we can just do day trips... I've actually heard lots of other... parents say they just don't do holidays, you know not much anyway, it's just too much, too much new input really."* Yet holidays of one type or another remain important for these families. *"I would never not take [John] and I think of course he benefits from the change..."* said Rachel, whilst Charlotte commented that whilst they do cause Rory *"a bit of trouble"*, he *"also gets a lot out of it, so we weigh it up."* Holidays were seen as an expected part of life, so their absence deprived the children of a normal activity (McCabe, 2009). *"We feel guilty if we don't do anything, you know, so every year you think 'oh no, we'd better think of something'"* (Lucy).

The majority of the women are lone parents on tight budgets and yet prioritised a holiday as a break from everyday life (Minnaert, 2014). *"There has to be a holiday in the summer holidays otherwise the whole thing would be a nightmare, so that he [Sean] gets to do different stuff [and]... doesn't get bored"* (Claire). Lucy concurred: *"We are getting a break and... getting him out because he would quite happily stay in his little room. Yeah, it's good and the benefits do outweigh the challenges because we are doing something as a family, which is important."* Holidays

offered both parents and children pleasure and normality: *"...it can be fun but you have to have a sense of humour... there's always someone who has had a worse experience than you but it can be quite funny... so that can make you feel more normal"* (Lucy). Holidays often simply allowed parents to escape the everyday, Lucy expressed this as: *"I just thought 'I really have to go on holiday... I want to go somewhere sunny, I want to go abroad to a hotel."* Above all, these holidays enabled children diagnosed with ASD to broaden their experiences beyond their highly routinized homes into less predictable, busy public spaces (Bellini, 2004). As Lucy said: they have *"to get used to the world out there so they need to go out"*; a sentiment endorsed by Maxine's comment that *"[Geraint] has to live in the real world"* and that travel has afforded him opportunities to face that challenge.

## **5. CONCLUSION**

The mothers in this study navigated the emotional dimensions of their family holidays through a range of strategies. Firstly, they chose destinations and accommodation, which provided detailed information on all aspects of the holiday to prepare their child in advance. Secondly, they selected quiet destinations and accommodation and thirdly, they packed familiar possessions that are important to the child's daily routine and ensured that the accommodation could provide for their child's needs (e.g. Wi-Fi and television). Some mothers also carried an identification card or official document from health or psychology services for their child to deal with public censure if the child's behaviour became too extreme or to confirm his entitlement to preferential attention, such as in theme park queues. Such strategies could be employed by other parents and, if we can appreciate the coping approaches of parents of children with a disability, these may "provide valuable insight for other families and parents" (Dodd et al., 2009, p.266).

Tourism researchers have much to do to provide such insight and to adequately connect disability, psychological health, distress and the family. This paper has contributed to the unfolding work on this area and, in focusing on developmental difficulties and psychological distress, has widened the scope of an evolving tourism literature exploring wellbeing and psychological health. The area of

psychological distress in general, and specifically in tourism, requires much more investigation since studies on disability too often assume that the “obstacles, barriers and constraints which face disabled people are identical across all people with a disability” (Blichfeldt & Nicolaisen, 2011, p.83). Our research has highlighted the unique context of autism and the challenges faced by mothers of children diagnosed with ASD, illuminating their complex care-giving responsibilities and the impact these have on family holiday experiences, including those of siblings. Whilst all the mothers we spoke with identified benefits to holiday-taking, they balance these against the disruption to routines and exposure to sensory-stimulating environments (Bellini, 2004), which make holidays a challenging experience for both them and their child or children. In addition, expectations to conform to certain behaviours and public reactions to their child’s behaviour can exacerbate the difficulties of holidaying and make them an isolating experience. In this, families with children diagnosed with ASD share common ground with other groups who experience stressful travel encounters in an unaccommodating world (Small & Harris, 2012). Embodiment, attitude, behaviours and stigma are common across disability groups and tourism’s gaze of discipline and surveillance, which causes such stress to many people with disabilities (Eichhorn et al., 2013) and to parents of young children in general, bears further scrutiny.

This leads us to perhaps the most thought-provoking contribution of our study. It illustrates the ways in which tourism experiences are journeys of mixed emotions: far from the binary of pleasure and apprehension, they are indeed multifaceted, complex, interlinked and intersubjective (Williams & Aaker, 2002). We need to know more in this area. We also require further explorations of the multiple, complex and nuanced meanings of ‘the holiday’; especially ones that investigate what constitutes a holiday for individuals and families who fall outside of our world’s increasingly unforgiving expectations and norms. Conceptualisations of the holiday have focused on its benefits and on its opportunities for positive transformation and renewal (e.g. Reisinger, 2013). Holidays also entail considerable ‘work’, anxiety and emotional labour (Dieffendorff et al., 2005), especially for care-givers, and particularly as here, for mothers of children diagnosed with ASD. At each stage of the



holiday and planning process, the women invested significant time, energy and emotional labour to facilitate trips for their families, in which they themselves experienced both stress *and* escapism. Indeed, different holiday practices (e.g. air transport, visiting resorts) evoke a series of different emotions and emotional labour depending on the life-world of our participants. With the consequences of emotional labour often resulting in psychological distress (Strazdins & Broom, 2004), we suggest more attention should be given to this area in future tourism research, alongside a more comprehensive account of gender and the lived experience of caregivers in the tourism context.

Finally, this study demonstrates a pressing need for research to raise awareness in the tourism industry of the needs of adults caring for children with developmental difficulties and the necessity to link tourism research and practice collaborations with existing mental health, wellbeing, respite care and resilience-building initiatives (e.g. Aumann & Hart, 2009) and legislation (e.g. Public Health Wales, 2016). There is immense potential in this space for innovative partnerships between tourism and therapeutic and clinical health professionals and social and community enterprises and organisations. The field needs much more research to examine stress and anxiety and its physical, psychological and emotional consequences on holiday; for the mothers in this study a messy affective mix of pressure and pleasure is very evident and wider comparisons can be drawn with mothers and fathers with young children, with people with disabilities and with older travellers, etc. Feelings are socio-spatially mediated and articulated and have the power to expand or contract horizons as “...human lived experience is constructed through emotion” (Pritchard et al., 2011, p.951). The experiences of the mothers here demonstrate how complex and conflicting feelings shape their holiday experiences as they respond, not just to the affective and practical needs of their children but to public expectations. Holidays are emotionally cluttered experiences and researchers in tourism, as in other fields (e.g. health and social policy and health economics), need to explore the role and meaning of such feelings from multiple paradigmatic, theoretical and methodological perspectives.

Table 1: Study Participants

Participant	Marital status	Occupational status	Son with ASD	Son's Age	Siblings
Charlotte	Divorced	Works part-time	Rory	9	None
Claire	Divorced	Full-time carer	Sean	11	1 sibling (also diagnosed with ASD)
Leanne	Married	Full-time carer	Owen	12	3 siblings
Lucy	Married	Works part-time	Joe	19	2 siblings
Maxine	Widowed	Full-time carer	Geraint	19	None
Rachel	Divorced	Works part-time	John	13	1 sibling

Table 2: Visual representation of the thematic spread for each interview

Participant	Son with ASD	Need for routine	Sensory relationships	Surveillance & emotional labour	Relaxation & holiday challenges
Charlotte	Rory	√		√	√
Claire	Sean	√			√
Leanne	Owen	√	√	√	√
Lucy	Joe	√	√	√	√
Maxine	Geraint	√	√		√
Rachel	John	√	√	√	√

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