

EXPERIENCES OF TOURISTS WITH INTELLECTUAL DISABILITIES: A PHENOMENOLOGICAL APPROACH

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ABSTRACT

This paper aims to explore ways in which adults with intellectual disabilities experience tourism. The study applies phenomenology and draws on in-depth interviews with participants with intellectual disabilities focusing on their lived experiences of tourism. The tourism experience was significant and meaningful to the participants, in that tourism provided a sense of 'normality,' encouraged self-efficacy, and strengthened relational connections. This paper advances theory by conceptualising the nature of the tourism experience through the authentic voices and lived experiences of adults with intellectual disabilities. This lens of intellectual disability addresses a scarcity of representation in existing tourism scholarship, augmenting and advancing inclusive understandings of tourism experiences for these individuals with disabilities.

Keywords: Accessible tourism, inclusive tourism, intellectual disability, phenomenology, social model of disability, tourist experience.

1. INTRODUCTION

Tourism scholarship, for the most part, has been remiss in its limited inclusion of the lived experiences of individuals at the margins of society (Kastenholz, Eusebio, & Figueiredo, 2015). One such marginalised group is people with disabilities (Devile & Kastenholz, 2018). With 15% of people living with disability globally, this population is significant (World Health Organization & World Bank, 2011), and “expected to increase as a result of increasing life-span, decreases in communicable diseases, improved medical technology, and improved child mortality” (Yau, McKercher, & Packer, 2004, p. 947). Despite tourism being recognised as a citizenship right for all (Minnaert, Maitland, & Miller, 2009), people with disabilities are still reported to participate disproportionately less than people without disabilities, in many elements of cultural life, including, the arts, sport and leisure (Darcy, McKercher, & Schweinsberg, 2020). There also remains a lack of understanding about tourism participation among people with different types of disabilities (McIntosh, 2020), most notably among those with intellectual disabilities and other non-mobility disabilities.

Largely, tourism is developed around the population without disabilities (Figueiredo, Eusebio, & Kastenholz, 2012). The industry lacks awareness and is complacent in their considerations of tourists with disabilities (Darcy & Buhalis, 2011; Darcy, Cameron, & Pegg, 2010), thereby leading to a general misconception that people with disabilities are unable to or do not want to travel (Domínguez, Fraiz, & Alén, 2013; Luiza, 2010; Porto, Rucci, Darcy, Garbero, & Almond, 2019). Tourism has long been recognised for its exclusive nature (Scheyvens & Biddulph, 2018) and over the years, work has accumulated to increase access to production, consumption, and benefits of the experience. “While some people with disabilities never travel, many others enjoy a full, active, and varied travel career” (Yau et al., 2004, p. 954). People with disabilities are exercising their right to travel (Darcy, 1998; Ray & Ryder, 2003), and there is a social imperative to serve this group of tourists (Richards, Pritchard, & Morgan, 2010). Their participation can afford a number of positive intrapersonal and interpersonal outcomes, namely psychological and physical health benefits, personal development and social inclusion (Blichfeldt & Nicolaisen, 2011; Innes, Page, & Cutler, 2016), which together enhance quality of life and life satisfaction (McCabe & Johnson, 2013).

To this effect, there is still an important need for tourism scholars to work “against the exclusion of under-empowered voices in our societies” (Richards et al., 2010, p. 1098) and, instead, work toward the creation of a dignified, just and inclusive industry and scholarship that considers the full range of heterogeneous voices. In other fields, such as disability studies, leisure studies and recreation studies, there has been a long-term commitment to, and richer connections with, issues relating to disability and intellectual disability. In this work, positive outcomes of leisure and recreation participation have been identified as individuals gain a sense of control, confidence and empowerment (e.g., Aitchison, 2003; Duvdevany & Arar, 2004; Patterson, 2001). Even while people with disabilities represent an emerging voice within tourism inquiry (Cohen, Prayag, & Moital, 2014; Daniels, Rodgers, & Wiggins, 2005; Richards et al., 2010), there remains scant attention to the voices of those with intellectual disabilities. Indeed, intellectual disability is often viewed as an afterthought added to organisational services and mainstream tourism considerations (Boxall, Nyanjom & Slaven, 2018). As such, this paper advances tourism research by conceptualising the meaning and significance of the tourism experience from the perspectives of adults with intellectual disabilities.

2. LITERATURE REVIEW

2.1 Disability and accessible tourism

Within the tourism literature, scholarly attention to tourism, disability and the concept of accessible tourism (Darcy & Buhalis, 2011; Eichhorn & Buhalis, 2011) has grown and evolved in its sophistication (Darcy et al., 2020). Accessible tourism “enables people with access requirements, including mobility, vision, hearing and cognitive dimensions of access to function independently and with equity and dignity through the delivery of universally designed tourism products, services and environments” (Darcy & Dickson, 2009, p. 34). While increased scholarly attention is being directed to the accessibility of tourism for people with disabilities, this agenda remains somewhat narrow in its focus (Hunter-Jones, 2006). Notably, most previous scholarship is managerial and market-based, rather than “holistically person-centered” to achieve an inclusive understanding of the meaning and experiences of tourism for individuals with disabilities (Richards et al., 2010, p. 1099).

Scholars, for instance, document the economic rationale supporting accessible tourism (Card, Cole & Humphrey, 2006; Cohen et al., 2014). Studies show that people with disabilities have the desire to travel (Cockburn-Wooten & McIntosh, 2021; Darcy & Dickson, 2009), the financial means to facilitate it (Stumbo & Pegg, 2005), and rarely travel alone (Yau et al., 2004). There is thus an important economic and social impact, given that they primarily travel with companions and/or carers (McKercher, Packer, Yau, & Lam, 2003; Ray & Ryder, 2003). Nevertheless, they are largely ignored by industry as a consumer group and as a viable segment of the market (Darcy, Cameron, & Pegg, 2010; Gillovic & McIntosh, 2015; Shaw & Coles, 2004). Other studies point to anecdotal evidence or provide best practice case studies of tourism operators and destinations that “actively pursue accessible tourism as a core part of tourism where it exists as both a market segment” (Darcy et al., 2020, p. 142) and as “part of every market segment” (Dwyer & Darcy, 2011, p. 222).

A review of the literature also shows that scholars frequently discuss the structural, interpersonal and intrapersonal barriers to people with disabilities’ participation in tourism (Blichfeldt & Nicolaisen, 2011; Cohen, et al., 2014; Israeli, 2002). Literature also identifies the role of assistive technologies and information in facilitating participation and removing social barriers (Eichhorn, Miller, Michopoulou, & Buhalis, 2008). As such, there has been work to remove barriers and to facilitate participation, whether by disability type and support needs (Darcy & Buhalis, 2011), or by industry sector and activities (Yau et al., 2004). Some scholars have argued that the intrinsic barriers are the most significant obstacles (Murray & Sproats, 1990; Smith, 1987). More scholars have argued that it is the structural barriers, and especially the social environment, that are the most profound and impactful deterrent to participation (Daniels et al., 2005; Daruwalla & Darcy, 2005; Innes et al., 2016). For instance, Richards et al. (2010) report that “many people with visual impairments simply chose to opt out of the anxiety and stress of travel because of the lack of empathy of the sighted world” (p. 1111). Examples like this contribute to disproportionately smaller numbers of people with disabilities, compared with people without disabilities, being able to participate fully in tourism (Darcy, 1998). Yet, overall, the lived experiences of tourists with different types of disabilities remain relatively less heard in accessible tourism scholarship.

2.2 Tourism experiences of tourists with disabilities

Tourism scholars are increasingly calling for an understanding of the unique voices and embodied lived experiences of tourists with disabilities (McIntosh, 2020; Richards et al., 2010; Small, Darcy, & Packer, 2012). Aitchison (2003) argues that much of the work of tourism and research assumes that “mobility and sight are deemed to be prerequisites for engaging with the tourist experience” (p. 962). Nevertheless, representations of the access tourist and the accessible tourism experience remain predominantly from the perspectives of people with physical disabilities or mobility impairments (e.g., Daniels et al., 2005; Ray & Ryder, 2003) albeit focusing on constraints, and without exploring their embodied experiences and emotions. More recently, however, there have been representations of people with sensory disabilities, especially vision impairments (e.g., Packer, Small, & Darcy, 2008; Richards et al., 2010; Small et al., 2012).

Despite a call for more inclusive tourism and research, such scholarship remains incipient and is not inclusive of people with disabilities beyond those with physical and mobility disabilities (Deville & Kastenholz, 2018; Gillovic, McIntosh, Cockburn-Wootten, & Darcy, 2018). This is, perhaps, because of the perceived difficulty in accessing or involving potential populations in the research process. The voices of people with invisible disabilities, for instance, remain relatively unexamined in tourism scholarship (McIntosh, 2020). Also neglected are tourists with intellectual disabilities (Mactavish, McKay, Iwasaki, & Betteridge, 2007). This gap persists despite wider bodies of work which consider their participation in the arts, sport, leisure and recreation, and report psycho-emotional and social benefits (e.g., Darcy & Dowse, 2013; Modell & Imwold, 1998).

There are, however, a few notable exceptions. For example, Amet (2013) examines the experiences of families vacationing with children diagnosed with autism spectrum disorder. Sedgley, Pritchard, Morgan and Hanna (2017) examine the emotional and everyday experiences of mothers vacationing with a child diagnosed with autism spectrum disorder. Mactavish et al. (2007) examine the role of vacations in enhancing the quality of life of families including a member with intellectual disability. McConkey and McCullough (2006) examine the benefits of organised holiday breaks for adults with intellectual disabilities living with older carers. This emerging body of work points to people with intellectual disabilities’ dependency on carers or companions to travel. Indeed, these studies, for the most part, present the perspectives of the carers or companions, rather than those of the individuals with intellectual disability themselves. Instead, what remains to be heard is the significance and meaning of tourism for these individuals, as expressed in their own way.

3. STUDY METHODS

This exploratory study conceptualises lived experiences of tourism from the perspectives of adults with intellectual disabilities. The study adopted a phenomenological approach, that was inductive and exploratory in its nature, and qualitative in its design. A phenomenological approach to research is ultimately concerned with the rich and complex diversity of the unique and subjective human experience (Hegel, 1949; McManus Holroyd, 2007). Phenomenological studies are integral to uncovering accessible tourism experiences by giving voice to tourists with disabilities (e.g., McIntosh, 2020; Sedgley et al., 2017). They are foundational in intellectual disability research too (Corby, Taggart, & Cousins, 2015; Lloyd, King, Lampe, & McDougall, 2001), by which much of the methodological and ethical considerations in this study were informed.

The participants were recruited through purposeful and professional criterion sampling (Lincoln & Guba, 1985; Patton, 2002), and followed a university approved ethical process. Over several months, we built relationships of mutual trust and understanding with disability service and support organisations in New Zealand regions with the highest rates of disability and international airports (Statistics New Zealand 2014). These organisations acted as gatekeepers, negotiating access to prospective participants (e.g., Iacono, 2006; Nicholson, Colyer, & Cooper, 2013), and disseminating our call for participants to their established networks and via their preferred communication channels. In addition, formal and informal carers of the adults with intellectual disabilities played an integral role in supporting the recruitment process, and determining (non)participation. In particular, they helped to communicate the information sheet, consent form and any accommodations and supports, all of which were designed to increase access with plain language, bullet points and images, consistent with inclusive research approaches (e.g., Milner & Mirfin-Veitch, 2012; Walmsley & Johnson, 2003).

The participants selected were adults (aged 18 years and over) who had travelled within the twelve months prior to interviewing, as this one-year time period was deemed appropriate to capture recency of experience, and to facilitate ease of reflection. Also, participants were selected for whom the primary nature of the impairment was intellectual (Beail & Williams, 2014; McDonald, 2012). These were individuals who self-identified or defined their own way of living with an intellectual disability, or who were identified as having an intellectual disability by their carers. As with criteria used in previous intellectual disability research of a phenomenological nature (e.g., Corby et al., 2015; Ottmann & Crosbie, 2013), the participants selected had a mild to moderate intellectual impairment, as opposed to severe or profound, high or complex. This was important, firstly, with regard to ethical concerns around the participant's capacity to comprehend the notion of, and communicate, consent (Boxall & Ralph, 2010; Cameron & Murphy, 2006). It was also important due to the qualitative nature of the research and its demands for rich narrative (Kafle, 2011). Ultimately, this criterion demanded a certain level of expressive-receptive communication abilities (Nind, 2008).

Phenomenological studies typically involve small sample sizes. This allows insights to be gained into the rich and personal meanings of a particular phenomenon (Szarcycz, 2009; Taylor & Bogdan, 1998). In total, nine participants were recruited, with varying types of mild to moderate intellectual disabilities. It should be noted that the study does not claim to treat intellectual disability homogenously nor does it claim to be representative of different types. That said, three of the participants had undiagnosed or general intellectual disabilities, and six of the participants also had associated intellectual disabilities, which included attention deficit hyperactivity disorder, brain injury, cerebral palsy, Down syndrome, epilepsy, fetal alcohol syndrome, Fragile X syndrome, polyarthritis nodosa. A profile of the participants is provided in Table 1.

To capture the participants' lived experiences and the significance they ascribe to tourism, the data was collected through person-centred, semi-structured interviews (Johnson, 2002; Kafle, 2011), as a proven method to engage people with intellectual disabilities (Ottmann & Crosbie, 2013). To prioritise the voices of the participants, both the content and process of the interviews were adapted to suit each individual's diverse needs (McDonald, 2012; Walmsley & Johnson, 2003). This allowed, for instance, varying levels of language and conceptual skills, as well as expressive-receptive communication abilities among the adults with intellectual disabilities (Beail & Williams, 2014; Milner & Mirfin-Veitch, 2012).

The interviews were conducted in a location of the participant's choice and where they felt comfortable and safe, which principally was in their home (Hall, 2013; Hillier, Johnson, & Traustadottir, 2007). The interviews lasted anywhere between fifteen minutes to two hours, and they were audio-recorded in order to capture the accuracy and detail of what was being said. The interviews were kept confidential and the participants' names were replaced with pseudonyms (Guenther, 2009). The activity of member-checking with people with intellectual disabilities is often neglected, given the practical challenges involved in doing so. Instead, throughout the interviews, we were active in our efforts to relay back the participants' responses and our interpretations of them, seeking confirmation of what was said and agreement with our interpretation (Hall, 2013; Nind, 2008). As "phenomenology asks the simple question, what is it like to have a certain experience" (van Manen, 1990, p. 44), we sought to find out 'what was important to the participants', and 'how that importance was understood' (Laverty, 2003).

We considered the wording and pronunciation of questions about their tourism experiences using clear and uncomplicated language that minimised the use of abstract concepts and temporal dimensions (Hall, 2013). The questions asked were the 'what' and 'how' of their experiences, rather than the 'why', which can sometimes come across as judgmental (Collard & Marlow, 2016). To help progress the conversation and seek clarity where needed, we were able to draw upon visual aids like photographs, scrapbooks and other personal belongings that the participants wanted to share (Boxall & Ralph, 2010). In a similar vein, the carers were present in some of the interviews, and were able to further facilitate the flow of conversation. Mostly, however, the participants were engaged and interacted well, seeming to enjoy the opportunity to share their tourism experiences.

The interview data was manually transcribed and analysed by the primary author using Braun and Clarke's (2006) phases of thematic analysis. This was an inductive, data-driven, iterative and recursive process, with much of the data collection and analysis occurring concurrently (Boyatzis, 1998; Joffe, 2011). The co-authors continuously engaged in conversations to verify the coding framework and structure, and concurred with the interpretation and construction of the phenomenon presented, as consistent with a phenomenological approach (van Manen, 1990). All the authors thus had a role in the research. While one author has lived experience of disability, all the authors have spent considerable time cultivating an awareness of, and capacity to engage with, adults with intellectual disabilities. Mostly, this has come about through their advocacy and relationships with the disability community and sector over several years.

Three key emergent themes were identified: (1) tourism provides a sense of 'normality'; (2) tourism encourages self-efficacy; and (3) tourism strengthens relational connections. The thematic spread across each participant's narrative is shown in Table 2. Importantly, the study did not seek common or definitive findings, and the findings cannot be generalised (Sedgley et al., 2017). Instead, the findings are exploratory and construct but one possible and preliminary interpretation of the nature of this particular human experience (van Manen, 1990).

4. FINDINGS AND DISCUSSION

Overall, analysis of the data revealed that the tourism experience was both significant and meaningful to the study participants. The sample was mostly comprised of active travellers who frequently travelled to domestic and international destinations alike, as well as three participants

who had travelled for the first time to a domestic or international destination, as Table 1 illustrates. All of the participants expressed a ‘like’ or ‘love’ of partaking in tourism. They made comments such as, *“I love travelling a lot in the world,”* and *“to be honest it was so much fun; I love travelling and I wish I could go back.”* Many of the participants also expressed a desire to travel again and more often in the future, making comments like *“I did love it and I want to go on another trip; go to other places I haven’t seen,”* and *“I really love going to holidays; I love travelling a lot in the world, it’s my big thing, I’ve realised I love going so much.”*

The participants in this study saw tourism as an opportunity to relax and have a break or to engage in new and novel experiences. The attractions visited and activities engaged in were especially memorable, including eating out, shopping, visiting art galleries, museums or the theatre, swimming, snorkelling or boating, hiking or sports. Theme parks were a particular favourite, as the following quote illustrates:

“I love Dream World. It’s lovely. I love all the rides there and I love the animals – except the tigers. Sea World is my second favourite. Wet and Wild is my third – obviously my favourite, but my third – but then Movie World, because there’s lots of things to do there.”

Indeed, previous studies highlight the hedonistic nature of tourism (Lieper, 2004), especially for tourists with disabilities (Shaw & Coles, 2004; Yau et al., 2004), who are then motivated to travel again and more frequently (Domínguez et al., 2013). Leisure studies have also suggested the significance, for people with intellectual disabilities, of activities outside of their usual environment (Badia, Orgaz, Verdugo, Ullán, & Martínez, 2013; Cummins & Lau, 2003).

4.1 Tourism provides a sense of ‘normality’

Analysis of the data revealed tourism as a means to provide a sense of ‘normality’ for the participants. Tourism was perceived as a welcome reprieve from the experiences of their somewhat constrained and repetitive daily lives. Most of the participants reported that their leisure was usually confined to activities at home, especially for those who lived with their parents, or weekly house outings and vocational services for those who lived in residential/supported living services. The participants’ desire to travel seemed to stem from comparisons made with people without disabilities. Not only did the tourism experience represent an opportunity through which they were able to participate, but it could reaffirm what they would perceive as having a ‘normal’ identity.

For example, a participant who was also a wheelchair user described how the act of being hoisted into an airplane seat made her *“feel like a normal person,”* as her wheelchair was what makes her disability visible to others. Interestingly, this would be contrary to some other studies that show air travel to be the opposite, that is, visible and dis-embodied for people with disabilities (e.g., Poria, Reichel, & Brandt, 2010). For one participant who sought to do the types of things her siblings were doing, partaking in tourism provided a sense of achievement, and was a way in which a degree of independence could be attained.

Indeed, previous scholars have suggested that, for people with disabilities, tourism can minimise feelings of indifference, distress or dependency that are often experienced in their everyday lives (e.g., Innes et al., 2016; Valtonen & Veijola, 2010), and can give a sense of ‘normality’ (Hunter-

Jones, Sudbury-Riley, Al-Abdin, Menzies, & Neary, 2020; McIntosh, 2020). These examples, among others, did not deny the fact that the participants' travel was still dependent upon a carer accompanying them. That said, scholars have reported that accessible tourism experiences can serve as sites of resistance and/or transformation (Eichhorn, Miller, & Tribe, 2013; Shelton & Tucker, 2005), wherein people with disabilities can attain, for instance, a greater sense of independence (Kim & Lehto, 2013; Pritchard, Morgan, & Ateljevic, 2011), or an understanding of what a 'normal' life might look like (e.g., Lehto, Luo, Miao, & Ghiselli, 2017; McIntosh, 2020).

This finding emphasises the need to better recognise and acknowledge, rather than discredit, the everydayness of tourism, as well as the extraordinariness of this activity. For people with intellectual disabilities, their everyday experiences can be disempowering, and therefore tourism can provide a 'new normal' that they may strive for when they are back home. The fact that tourism can offer a taste of normality in an extraordinarily full way thus adds to the meaningfulness of the experience for people with intellectual disabilities, and perhaps even lends itself to enhancing the quality of life and life satisfaction, as scholars have evidenced (Mactavish et al., 2007; Stock et al., 2011).

4.2 Tourism encourages self-efficacy

The second theme that emerged from the data analysis related to the participants' recognition that tourism encourages self-efficacy. Participants commented on a sense of competency and confidence in themselves, as illustrated in the following quote, *"your ability to realise that you can exist as an adult in the world; travel is the best way to learn a new language of confidence."* Many of the participants achieved personal goals, cultivated growing passions, uncovered new interests and tried new things, for instance: *"I tried on my own, some snails – the frogs legs, they're the ones that everyone says tastes like chicken – the snails are more like mushrooms,"* and *"when I first started going to Australia, I couldn't do the Giant Drop but I did it anyway; I'm scared to get over my fear of heights but I'm actually going to go bungee jumping off the bridges."* Such outcomes rendered self-efficacy through feelings of accomplishment and fulfilment among the participants, as the following quote illustrates:

"I love Sea World – I think it's the dolphins – it just inspires me to do a bit of biology to do with the marine life. How they adapt when they get caught in the nets and stuff, and how I could, as a biologist, prevent that. I think I would really love to study them."

Accessible tourism scholars have also reported that "being able to travel is a meaningful task" (Yau et al., 2004, p. 958). The experiences allow people with intellectual disabilities to be storytellers in the same way that their families and friends convey their own stories about tourism. The experience facilitates personal development and empowerment for people with disabilities, and these intrapersonal outcomes give rise to a sense of confidence and achievement (e.g., Blichfeldt & Nicolaisen, 2011; Kim & Lehto, 2013; Luo, 2014).

The tourism experience also encouraged intellectual development, through moments of learning that expanded the participants' worldviews and offered new frames of reference for them to draw upon. Participants commented: *"I love travelling because I love history a lot; new culture, new people, and new, different ways, when you travel a lot,"* and *"I think travel should be considered*

not so much as a luxury item but as a fundamental aspect of expanding your horizons; the ability to do it enhances yourself and your sense of psychology and wellness.”

Interestingly, the experiential nature of tourism, and the unique context within which it takes place, transmitted tacit knowledge in a more tangible way. An example of this related to those participants who engaged in sequential tourism experiences, where they acquired an increased familiarity with and autonomy in navigating the processes of the tourism system, whether that be completing forms for immigration and making their way through the e-passport photo recognition technology, or dropping and collecting baggage pre- and post-flight. One participant commented, for example:

“When you go through the borders you need to tip water out of your bottle because they think it’s a firearm or something; people know that if the sniffer dog sits down next to me, I’m smuggling something.”

Previous literature shows tourism to be an experience that encourages learning moments among people with disabilities (e.g., Kim & Lehto, 2013; Lehto et al., 2017; Minnaert et al., 2009). Other scholars, too, have identified that the travel skills acquired with experience allow for more self-confidence in tourism participation (e.g., Blichfeldt & Nicolaisen, 2011; Yau et al., 2004), and “allow the individual to deal with obstacles in a more positive and knowledgeable way” (Devile & Kastenholz, 2018, p. 271). It could be said that engaging in sequential tourism experiences means that people with intellectual disabilities, too, like the people with mobility and visual impairments in Yau et al.’s (2004) study, gain their own travel career ladder (Pearce & Caltabiano, 1983).

4.3 Tourism strengthens relational connections

The third theme that emerged from the data analysis revealed that tourism facilitated positive inter-personal outcomes for the participants, and enhanced their social interaction and inclusion. Specifically, relational connections included both those with their carers and those with others back home. Particularly with other people back home, the topic of tourism provided common ground and assisted the individuals with intellectual disabilities in connecting through conversation, which gave rise to feelings of belonging, as the following quote illustrates:

“Now I can have a dialogue with my friends that is on par with them – that’s a dialogue I wouldn’t have been able to have if I hadn’t travelled. It puts me in a different frame of reference – I’m not just the ‘poor disabled person’ – I am somebody who has done some of these things and has valued them as equally awesome.”

Among the stimuli for these shared conversations were the photos that they had taken. Participants commented, for instance: “*sometimes I do take pictures on my phone – I love sharing stories with my friends in my life,*” and “*of course it’s very special for me – I love my memories – I think it was an amazing experience for me.*” Scholars have reported the beneficial social outcomes of tourism for people with disabilities (e.g., Hunter-Jones, 2003; Kim & Lehto, 2013). The ability to reflect on and share memories and photographs of the experience in conversation with others, especially, creates a space for connection and engenders belonging (e.g., Lehto et al., 2017; Lloyd et al., 2001).

The shared tourism experience had positive social outcomes for the participants and their carers, facilitating friendship and deepening relational bonds. One participant reflected, for example, “*it was nice for her to come with me – she was happy to do it and she’s actually fun – if I go on more holidays, I’ll take her.*” As family tourism scholars have noted, a positive and enjoyable tourism experience stems from the sociality of being together (Carr, 2011; Larsen, 2008); from spending quality time together, having new experiences and making memories (Gram, 2005; Lehto, Soojin, Yi-Chin, & MacDermid, 2009). Similarly, some accessible tourism scholars have noted such outcomes in their research on families with members with disabilities (Lehto et al., 2009; Mactavish et al., 2007), while others’ experiences have been more mixed (Sedgley et al., 2017).

It is useful to emphasise here that all of the participants in this study were engaging in independent travel with an unpaid, informal carer (i.e. mum, sister or friend), and in some cases, additional family members, or a formal, paid carer (i.e. support worker), as indicated in Table 1. The following quote from a participant is an example: “*I will travel with companions for the rest of my life. I will always be at this level of independence; there is going to be no cheesy Hallmark movie of my grand recovery.*” While for some participants, this dependency related to functional mobility and personal care, for most, it related to their expressive and receptive communicative abilities, as well as their cognitive capacities for comprehension. Travel is not independent for these adults with intellectual disabilities. This contrasts with much literature that assumes travel is independent and, therefore, a key implication of this theme is around dependence, and there is a need to more carefully examine the care relationship in tourism. As such, a positive and strengthened relational experience is not only critical but a further benefit and meaningful aspect of tourism for this group of tourists.

5. CONCLUSIONS

This paper serves to contribute to the growing body of work on accessible tourism by providing original insights into the meaning tourists with intellectual disabilities ascribe to tourism. In this way, the paper moves beyond the predominant focus on tourism by those with physical and mobility disabilities, and contributes to an understanding of the plurality of lived experiences of disability. What is original is the inclusion of the perspectives of tourists with intellectual disabilities that have not previously been heard. Indeed, there is an important need to further advance tourism theory through the inclusion of their voice with the aim of moving their lived experience from the margins to occupy a space in more inclusive tourism research, as well as in considerations within the tourism industry more generally.

While some other fields have provided insight into the leisure and recreation experiences of people with intellectual disabilities, their lived experiences of, and potential barriers in, accessing the tourism system may be more pronounced. In fact, it could be argued that this group of people, compared to other dimensions of disability, might be even less likely to partake in tourism. However, the narratives of the participants in this study point to the contrary: they do partake in tourism and the experience still is meaningful (although a caveat must be made that their intellectual disabilities were mild to moderate in nature). For them, accessing the commercial tourism system was important for providing a sense of normality, encouraging self-efficacy, and strengthening relational connections, and they aspired for future travel. The lack of access to and participation in tourism for people with disabilities has been expressly identified in the United Nations *Convention on the Rights of Persons with Disabilities* (2006). Therefore, feelings of being able to realise a ‘normal’ life and also aspire to a ‘good life’ for this group of

tourists hold important considerations for the industry (Hermsen, Embregts, Hendriks, & Frielink, 2014).

To this end, it is hoped that this study contributes an industry awareness of both the business and social cases supporting meaningful engagement in tourism for people with intellectual disabilities and those they choose to travel with. In recognising this, the industry must further the development of accessible tourism products, services, and experiences. Where appropriate, the industry could provide relevant information, making it accessible by communicating in plain language or ‘easy English’. This includes having knowledge of the augmentative and alternative communication (AAC) and assistive technologies that people with intellectual disabilities can require. More inclusive approaches and strategies for such tourism will require engagement with accessible tourism stakeholders to raise awareness and understanding of this group and their needs, through the likes of advocacy, training, and education, to reduce the stigma often associated with intellectual (and often invisible) disabilities, and to cultivate empathy (McIntosh, 2020). We concur with other scholars who purport that people with [intellectual] disabilities have diverse consumption patterns, and are an important segment of the tourism market who require greater attention to their social inclusion (Cohen et. al., 2014; Eichhorn & Buhalis, 2011).

We recognise a limitation of this study is that the sample were able to partake in tourism, albeit not independently, and had mild to moderate intellectual disabilities rather than more complex needs. It is important too, that the voices of people with more severe or complex intellectual disabilities are heard. Future research might consider augmentative or alternative communication measures (AAC) to improve the conveyance of communication (Nind, 2008), or visual methods – like photovoice – that encourage more meaningful participation (Schleien, Brake, Miller, & Watson, 2013). Alternatively, it might draw upon a mediated approach, whereby the carers of people with intellectual disabilities are involved. The carer might, for instance, facilitate the interview process as a ‘proxy’ for the individual, or alternatively, their voice might be included as a participant in their own right (Cummins & Laraine Masters, 2002).

We also recognise this study was conducted within a western cultural context (Mactavish et al., 2007), and that all of the participants had the financial means to travel, as well as the willingness of their carers to support them (Brewster & Coleyshaw, 2010). The participants were therefore able to successfully negotiate the common interpersonal and structural barriers to tourism that prevent many other people with disabilities from participating. It is well-documented that people with [intellectual] disabilities are limited by the financial, emotional and social means that are required in order to partake in tourism in the first instance (Hunter-Jones, 2010; McKercher & Darcy, 2018; Shaw & Coles, 2004). Future research might therefore also consider the nature of organised holidays for people with intellectual disabilities, or recreational respite for their carers, especially noting that such initiatives have been established elsewhere (e.g., McConkey & McCullough, 2006; Pinquart & Sorensen, 2006). As carers and companions are important facilitators of tourism participation (Packer et al., 2008; Yau et al., 2004), there remains a need to further examine the relational experiences of tourism between tourists with intellectual disabilities and their formal or informal carers (Rogers, 2016).

Ultimately, as tourism researchers we need to give greater attention to how we engage and empower people with [intellectual] disabilities in an attempt to understand their lived experiences.

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Table 1. Profile of participants

Pseudonym	Gender	Age	Home area	Housing arrangement	Occupation	Income range	Travels with	Travel nature	Travel frequency
Anastasia	Female	18 – 24 years	Waikato	Living with parents	Unemployed	Less than \$20,000	Mum	Domestic and international	Active
Brooklyn	Female	18 – 24 years	Auckland	Living with parents	Employed [casual]	Less than \$20,000	Mum	Domestic and international	Active
Chloe	Female	25 – 44 years	Auckland	Living with parents	Employed [part-time]	Less than \$20,000	Friend	International	First-time
Jacob	Male	45 – 65 years	Bay of Plenty	Residential/supported living service	Unemployed	Less than \$20,000	Support worker	Domestic	First-time
Liam	Male	45 – 64 years	Waikato	Residential/supported living service	Unemployed	\$20,001 - \$40,000	Sister	Domestic and international	Active
Maggie	Female	25 – 44 years	Waikato	Residential/supported living service	Unemployed	Less than \$20,000	Support worker	Domestic	First-time
Mason	Male	18 – 24 years	Otago	Living with parents	Unemployed	Less than \$20,000	Mum	Domestic and international	Active
Oliver	Male	45 – 65 years	Bay of Plenty	Residential/supported living service	Employed [casual]	\$20,001 - \$40,000	Support worker	International	First-time
Sadie	Female	25 – 44 years	Waikato	Residential/supported living service	Unemployed	Less than \$20,000	Mum	Domestic and International	Active

Table 2. Thematic spread across each interview participant

Pseudonym	'Normality'	Learning	Relational connections
Anastasia	✓	✓	✓
Brooklyn	✓	✓	✓
Chloe	✓	✓	✓
Jacob		✓	✓
Liam	✓		✓
Maggie		✓	✓
Mason	✓	✓	✓
Oliver	✓		✓
Sadie	✓	✓	✓