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INTRODUCTION

ASPIRATIONAL BEGINNINGS

Readers of this text may be familiar with the terms ‘the disabled tourist’, ‘the tourist with disability’, or the broader categorisation of ‘the access tourist’. Throughout this book, we insert a “/” after the ‘dis’ in disabled, to draw important attention to the binary situation of those who live with or without disability. By highlighting the ‘dis’, we emphasise the need to move beyond binary thinking to raise awareness of the reality that those people who live with disability are also ‘able’ to assume the role of tourist. “The power of language is overwhelming” (Corbett, 2013, p. 2) and the need for social change underlines our choice of terminology. We chose to write this book about the dis/abled tourist to locate our discussion firmly within the context of disability, and with a wider desire to challenge the normative structures of a disabling and ableist (tourism) world. This world is exclusionary, marginalising and dis-abling, yet it has the potential to become one that is inclusive, dignifying, enabling, and empowering. Without attention to dismantling the normative structures, and a focus on enabling accessibility and inclusion through changes to infrastructure, industry, and care provision (Michopoulou et al., 2015), an individual with disability may be unable to take on the role of tourist and remain *disabled*.

As such, we come together as three critical scholars who share an aspiration for a more humanised tourism academy and world. Our intention to act in allyship with people with disability (Coons & Watson, 2013; Walmsley & Johnson, 2003), “being with and for the other” (de Laine, 2000, p. 16), serves as the inspiration for this book. As a research team, we have been able to connect, meld, and share our personal histories and lived experiences, and the injustices of disability and tourism research. Indeed, this book presents a composite of some of our research, borne out of our relationships with the disability community and critical understandings of their lived tourist experiences. We hope, through this book, that readers are encouraged “to cast a more critical eye over the issues of inequality and injustice that tourism may perpetuate, but also on the ways in which tourism offers possibility and potentiality to transform” (Gillovic, 2019, p. 249).

A book on the dis/abled tourist allows us to “make space for the marginalised” (Russell-Mundine, 2012, p. 4), represent their voices with integrity, and raise critical points for reflection and change to destabilise what is largely a disabling and ableist (tourism) world. These aspirations shape this book and aim to catalyse a closer synergy between academic theory and lived experiences. For this reason, throughout the book we

prioritise the lived experiences of the communities with whom we, and others, have built relationships and engaged in research. In this chapter, we set the scene by introducing readers to the definitions and context of disability, the significant barriers posed to participation in tourism, and the means to enable accessibility and inclusion.

THE DIS/ABLED TOURIST

It is important to first conceptualise disability. Globally, there are 1.3 billion people with disability (World Health Organization [WHO], 2023), and over three billion people who are their family, friends, and carers (Return on Disability, 2014). Taken together, these figures tell us that more than half of the world's population are directly or indirectly affected by disability (Return on Disability, 2014). The incidence of disability varies by region and by country. Disability is both a cause and a consequence of poverty, and it disproportionately affects more vulnerable and disadvantaged populations (WHO & World Bank, 2011). Eighty percent of people with disability live in less developed countries, or the Global South, in a state of poverty, and with limited or no access to healthcare, education, and employment (Darcy et al., 2010; Daruwalla & Darcy, 2005). By contrast, 10 to 20% of the total population of developed countries, or the Global North, live with disability (Darcy et al., 2020).

The prevalence of disability is growing worldwide. This is due to lower rates of child mortality and higher life expectancies, more chronic health problems and non-communicable diseases (Bowen et al., 2002), an ageing population (United Nations [UN], 2015), and better disability measurement tools (WHO & World Bank, 2011). Disability can occur at any time during a person's life, whether at birth; through accident, injury, or illness; or later in life (WHO & World Bank, 2011). Disability, therefore, may be short-term or long-term, temporary or permanent, episodic, or multiple (Darcy & Dickson, 2009; WHO & World Bank, 2011). Disability is indeed a part of the human condition, inevitably entering the lives of most people, be it in a temporary or permanent capacity, and whether directly for an individual or indirectly for someone close to them (Darcy & Dickson, 2009).

Definitions of disability are "complex, dynamic, multidimensional and contested" (WHO & World Bank, 2011, p. 3). There is no single definition of disability; rather, it is an evolving concept (UN, 2006a). It happens when people with disability face attitudinal and environmental barriers in a world that has largely been designed by and for people without disability (Bogart & Dunn, 2019; Figueiredo et al., 2012). This hinders their full and effective participation in society (UN, 2006a). Disability is defined by major medical and allied health organisations as "any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner within the range considered normal for a human being" (WHO, 1980, p. 28). This definition covers three dimensions: impairment, activity limitations, and participation restrictions (WHO, 2001). Impairment describes a problem in body structure or mental functioning (WHO, 2001). Activity limitations describe the difficulties encountered when executing a particular action (WHO, 2001). Participation restrictions describe problems affecting involvement in normal daily activities (WHO, 2001). Disability is therefore a complex phenomenon that reflects the

interaction between features of a person's body and features of the society in which a person lives (Darcy & Dickson, 2009). We will interrogate this definition of disability further as the book progresses.

The disability experience varies greatly, affecting a diverse group of people with a wide range of needs. Disability can affect a person's hearing, vision, or movement; memory, thinking, or learning; communication and relationships; and mental health (Darcy & Buhalis, 2011; Small & Darcy, 2011). People with disability are "those [individuals] who have long-term physical, mental, intellectual or sensory impairments" (UN, 2006a, p. 4). The result of the impairments is the experience of disability and what the implications of this are. Physical impairments have implications for mobility, dexterity, or stamina (Darcy & Buhalis, 2011; Domínguez et al., 2013). Sensory impairments have implications for hearing or vision (Darcy & Buhalis, 2011; Domínguez et al., 2013). Intellectual impairments have implications for comprehension, communication, and learning (Darcy & Buhalis, 2011; Domínguez et al., 2013). Psychological or psychiatric impairments have implications for mental health and wellbeing (Darcy & Buhalis, 2011; Domínguez et al., 2013). Within both the everyday as well as the tourism context, people with disability have different types of impairments, varying levels of support needs (for instance, independent, low, medium, high, or severe) (Blichfeldt & Nicolaisen, 2011; Darcy & Buhalis, 2011; Figueiredo et al., 2012), as well as a variety of motivations and desired experiences (Michopoulou et al., 2015). "There is no single figure of disability" (Breckenridge & Vogler, 2001, p. 352). Therefore, the heterogeneity and plurality of disability should be noted, and we take this diverse view of disability when we refer to 'people with disability' throughout this book, rather than the way that many scholars have regarded disability as a homogenous group.

There are both economic and social rationales supporting accessibility and inclusion in tourism (Rubio-Escuderos et al., 2021; Smith et al., 2013). The global tourism market of people with disability is neither niche nor small; it is a large market that is set to continue and grow due to population ageing. This market has a spending ability of US$1.9+ trillion (Return on Disability, 2014). The average travel group size for people with disability and their families, friends, and carers is 2.5 people, meaning their spending power is significant (Tourism Research Australia et al., 2018). There is a strong business rationale supporting the accessibility and inclusion of people with disability in tourism (Benjamin et al., 2020; Darcy et al., 2020). The economic benefits are well reported, and include greater rates of capacity, occupancy, and utilisation; heightened competitive advantage, market share, and profitability; and enhanced customer activity and loyalty (Card et al., 2006; Shaw & Coles, 2004; Stumbo & Pegg, 2005). International data confirms the following key characteristics of this market in Table 1, below.

Table 1. Key characteristics of the global tourism market of people with disability

It is neither niche nor small; it is a large market that is set to grow.
It reflects an ageing and affluent demographic: people are more likely to be aged 65 years and over.
Whilst the most prevalent impairment is mobility, many people have multiple impairments.
Share similar characteristics to people without disability in terms of motivations, accommodation types, and activities.
Average travel group size is 2.5 people.
Day visitor spending is particularly high.
Most people with disability take a domestic trip every year.
People with disability travel frequently, stay longer, and spend more than the average individual without disability.
People with disability are loyal and return to tourism offerings that support their requirements.
People with disability need accurate, up-to-date information about accessibility in order to plan their travel.
People with disability use websites and apps to book travel more than people without disability.
Previous experience and word-of-mouth are the most important sources of information for people with disability.
People with disability look for deals and offers for their companions and carers.
More people with disability would travel if industry improvements were made.

(adapted from Gillovic & McIntosh, 2022).

Being able to participate in tourism is a human right (McCabe & Diekmann, 2015; McCabe & Johnson, 2013). People with disability want and are exercising their right to access and enjoy tourism (Blichfeldt & Nicolaisen, 2011; Yau et al., 2004), which is considered to be an integral part of modern life (Bélanger & Jolin, 2011; McCabe et al., 2010; Shaw & Coles, 2004). Their participation in such experiences can provide positive intrapersonal and interpersonal outcomes, such as self-development or social inclusion, and they can feel free, in control, able, and confident (Figueiredo et al., 2012; Moura et al., 2022; Moura et al., 2017). International conventions, like the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD) (UN, 2006a), and legislation within some individual countries, provide human rights frameworks to promote the full and equal enjoyment of people with disability in participating with dignity, equity, and inclusion in tourism (Michopoulou et al., 2015; Richards et al., 2010; Shaw & Coles, 2004; Stumbo & Pegg, 2005).

INACCESSIBLE AND EXCLUSIONARY TOURISM INDUSTRY

Despite human rights frameworks and some country-specific legislation, there remain significant barriers to participation in tourism for people with disability (Eichhorn et al., 2008; Michopoulou & Buhalis, 2013). "This indicates that tourism is not equally accessible to people with and without disabilities and that members of the former group may be denied an important social right" (Dempsey et al., 2021, p. 1). Tourism, for the most part, is developed by, and delivered for, people without disability (Aitchison, 2009;

Figueiredo et al., 2012; Kastenholz et al., 2015). Barriers are "factors in a person's environment that, through either their absence or presence, limit functioning and create disability" (WHO & World Bank, 2011, p. 214). Often, multiple barriers will occur simultaneously, making functioning difficult (Daniels et al., 2005). While many tourists face some barriers to accessing and participating in tourism experiences, these are particularly amplified and unique for people with disability (Darcy, 2010; McKercher & Darcy, 2018). An individual's participation in tourism depends on the interaction between the embodiment of their impairment and the accessibility of the industry's different environments (Darcy & Dickson, 2009; McKercher & Darcy, 2018; Packer et al., 2007). Barriers, therefore, might be physical, communicative, informational, or attitudinal (Devile & Kastenholz, 2018; Eichhorn & Buhalis, 2011).

Physical constraints and barriers refer to aspects of the tourism supply chain, such as transport or accommodation, that are inaccessible; or, in the destination itself, barriers such as steps, and narrow or crowded spaces (Michopoulou & Buhalis, 2013). Informational barriers refer to the lack of accurate or reliable information around the level or nature of accessibility, such as out-of-date information on a website (Darcy, 2010; Eichhorn et al., 2008). Related to information are communicative barriers, which refer to information that is difficult to read, hard to understand, or published in limited formats (Figueiredo et al., 2012; Kong & Loi, 2017). Examples of this include publications using technical language or small font size, or those not available in Braille or with captioning or sign language. Last, attitudinal barriers refer to the lack of awareness and knowledge among tourism providers, as well as the negative and discriminatory attitudes across society (Daruwalla & Darcy, 2005; Zhang et al., 2019). Such attitudes manifest in assumptions about people's abilities, stigma and stereotyping, and prejudice and discrimination (McIntosh, 2020; Sedgley et al., 2017). The portrayals of disability throughout history uncover how deeply ingrained these attitudes and stereotypes are, and indicate the underlying discrimination people with disability, as a group, face today (see Braddock & Parish, 2001; Stiker, 2019).

Barriers can prevent full participation or present significant obstacles to be navigated. As such, people with disability need to engage in considerable pre-planning to find the information they need to ensure every element of a trip is accessible to them (Darcy & Buhalis, 2011). If one element of the journey is inaccessible, or poses significant barriers, they may not be able to travel at all (Daniels et al., 2005; Lee et al., 2012; Packer et al., 2007). In addition, hostile social attitudes and stigma may negatively affect the nature of the experience they have during travel (Innes et al., 2016; Richards et al., 2010; Small, 2015). Moreover, scholars are increasingly revealing the often disembodied, undignified, and dehumanised experiences of travel for people with disability because of the barriers they face – and through their agency and resilience, negotiate – during travel (McIntosh, 2020; Richards et al., 2010; Small et al., 2012).

ENABLING ACCESS FOR THE DIS/ABLED TOURIST

To overcome barriers, access must be enabled, and transformative solutions found for the dis/abled tourist. "Accessible tourism is not the future of tourism, but the future of

tourism is less promising without accessible tourism" (Smith et al., 2013, p. 9). Accessible tourism enables people with access requirements – whether they be mobility, vision, hearing, cognitive, or otherwise – to engage independently and with equity and dignity in tourism (Darcy & Dickson, 2009). This definition is inclusive of all people including those travelling with children in prams and seniors, as well as the families, friends, and carers who may travel with them (Darcy & Dickson, 2009). "No one is ever more than temporarily able-bodied" (Breckenridge & Vogler, 2001, p. 356). As such, the definition highlights a whole-of-life approach wherein most people, throughout the course of their life span, will benefit from the provisions brought about through the inclusion of accessible tourism initiatives (Darcy, Dickson, et al., 2021).

Accessibility, which we discuss in Chapter 5, "From good intentions to positive action," in relation to the UNCRPD (2006) definition, refers to the design of products, services, or environments for people with disability. It is about the ability of people with disability to engage with, use, participate in, and belong to, the world around them, such as through universal design (Gillovic & McIntosh, 2020). The antidote to the barriers mentioned above is that which enables access. Information must be accurate, reliable, and useful to people with disability, and the sources that information and other communicative material come from must be accessible (Buhalis & Michopoulou, 2011; Darcy et al., 2010). The social environment must also be welcoming, wherein local residents, other tourists, and tourism professionals display appropriate awareness of, and attitudes towards, people with disability (Figueiredo et al., 2012). Lastly, the physical barriers of the tourism supply chain or destination can be minimised and made more inclusive through universal design (Michopoulou et al., 2015; Nyman et al., 2017; Preiser & Ostroff, 2001).

Universal design is a reaction to, and critique of, conventional design that rarely considers a user's interaction with and in the material world (Centre for Excellence in Universal Design, 2020b; Poli, 2019). "Universal design is the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability or disability" (Centre for Excellence in Universal Design, 2020c, para. 1). It is not a design style; rather, it is an orientation to any design process that starts with a responsibility to the experience of the user (Centre for Excellence in Universal Design, 2020b; Poli, 2019). Most simply, it is the human-centred design of everything and for everyone (Centre for Excellence in Universal Design, 2020b; Darcy & Dickson, 2009).

Universal design is assessed against its accessibility, usability, and understandability, and is underpinned by seven principles (Centre for Excellence in Universal Design, 2020c). Equitable use means that designs "are useful and marketable to people with different abilities." Flexibility in use, means that designs "accommodate a wide range of individual preferences and abilities." Simple and intuitive use means that designs "are easy to understand, regardless of a user's experience, knowledge, language skills, or current concentration level." Perceptible information means that designs "communicate necessary information effectively to a user, regardless of ambient

conditions or an individual's sensory abilities." Tolerance for error "minimises hazards and adverse consequences of accidental or unintended actions." Low physical effort means that designs "can be used efficiently and comfortably, with a minimum level of fatigue." Size and space for approach and use means that "appropriate size and space is provided for approach, reach, manipulation, and use, regardless of an individual's body size, posture, or mobility" (Centre for Excellence in Universal Design, 2020a, paras. 2-8).

In some tourism destinations, elements of universal design are found in national building codes, accessibility standards, and disability discrimination legislation; however, the reality is that they are not always operationalised (Darcy et al., 2011). Tourism businesses and destinations need to view access as "central to a design rather than an add-on for compliance reasons" (Darcy & Dickson, 2009, p. 34). Implementing the principles of universal design into the planning, development, and delivery of tourism offerings will benefit not just people with disability but everyone (Darcy et al., 2010), as it considers occupational and safety issues, improves the quality of service, generates visitor satisfaction, expands the market base, reduces the effects of seasonality, and contributes to destination competitiveness and sustainability (Darcy & Dickson, 2009; Dominguez Vila et al., 2015).

STRUCTURE OF THE BOOK

Following the introductory context provided here, Chapter 2, "Disability and the Dis/abled Tourist Experience," conceptualises disability within the context of the tourist experience. Our discussions are framed within a need to move people with disability from the margins to inclusion (Kastenholz et al., 2015). We give careful thought to historical and contemporary definitions and discourses of disability, recognition of the heterogeneity of disability, and the need for inclusive language. We approach disability in the tourist experience through a lens of ethics and justice, and position it within the critical and moral tourism turns. We argue for a new set of future research considerations to move this agenda forward.

Chapter 3, "The Meaning and Experience of Travel," provides important understanding of the meaning and experience of travel for people with disability. We highlight different dimensions of disability, unveiling what people with disability sense and emotionally feel as they navigate an inaccessible tourism environment. We prioritise the lived travel stories of people with disability to engender their agency through negotiating the constraints and barriers they face on every trip they take in order to achieve the experiences they seek at a destination, and empowerment within such tourist experiences.

Chapter 4, "Care and the Dis/abled Tourist," reflects on care as it relates to disability and the tourist experience. We posit care as both a practice and an ethic. Drawing on the lived experiences of carers, we reveal care as an activity that is both informal and formal, personal, and organised – and one that is emotionally and relationally nuanced. For those people with disability who are unable to travel independently due to the nature of

their disability and level of support needs, travelling with a carer is another nuanced dynamic that people without disability do not experience.

Chapter 5, “From Good Intentions to Positive Action,” presents a call to action. It proffers future directions for both industry and advocates to champion social change, to challenge, deconstruct, and engender more meaningful and equitable participation in tourism. We consider aspirational best practice for the tourism industry to become more accessible and inclusive through guidelines, legislation, and communities of practice.

In Chapter 6, “Conclusion,” we end the book by challenging tourism scholars to engage in transformational research that prioritises inclusive processes and critically considers researcher positionality and their relationships with and within the disability community. The intention is to not only highlight the ‘dis’ in disabled tourist but to remove the marginalising label completely.