

## FAMILY TRAVEL EXPERIENCES WHEN ONE MEMBER HAS A DEVELOPMENTAL DISABILITY

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### Abstract

This paper presents initial findings from an investigation into the travel experiences of families where one family member has a developmental disability. In order to gain in-depth information on the subject, a survey and a small group interview were conducted with attendees at an international conference for family members of individuals with developmental disabilities. During the interviews, informants described their experiences of traveling with their family member with a developmental disability. Family members' disabilities included Autism Spectrum Disorders and Down syndrome. Key themes and concepts that emerged included: preparations for travel, family members' responses to travel, and family needs when traveling. Findings from this preliminary study supported the hypotheses that individuals with developmental disabilities do travel and that they have unique needs which, if addressed, can enhance their travel experiences. Suggestions for future research include assessing the tourism industry's knowledge of and preparedness to provide services for individuals with developmental disabilities, and developing an action plan to involve and educate tourism service providers.

### 1.0 Introduction

There is considerable research on travel-related issues for people with physical disabilities (Burnett & Bender-Baker 2001, Darcy 2002, Yau et al. 2004), but little is known about the travel experiences of families [where one member](#) has a developmental disability (Woodside & Etzel 1980). With increasing public awareness and growing public acceptance of individuals with developmental disabilities, this target group represents a segment of the traveling population that is likely to grow significantly in the years to come. At the present time, persons with developmental disabilities represent an under-acknowledged segment of travelers with unique travel needs. Improved understanding of the needs of individuals with developmental disabilities during travel could lead to improvements in access to services, safety, and customer satisfaction.

The Centers for Disease Control and Prevention (2004) define developmental disabilities as: "a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living" (para. 1). A review of the literature yielded no studies that addressed the travel experiences of people with developmental disabilities and their families. In the tourism literature, a few researchers have addressed accessibility (Darcy et al. 2010) and constraints to travel due to disability (Turco & Stumbo 1998). Most often these studies, however, address physical disabilities such as visual impairments and mobility constraints. Researchers have also addressed the role of leisure in the lives of individuals with developmental disabilities (Rogers et al. 1998), family quality of life when one family member has a developmental disability (Werner et al. 2009), and family leisure patterns among families with one developmentally disabled member (Dodd et al. 2009). However, the specific role of *family leisure travel* has not been addressed within the disabilities literature and the role of travel for individuals with developmental disabilities and their families has not been addressed within the tourism literature. This study aimed to promote an awareness of the needs of this population within the tourism industry.

### 1.1 Conceptual Model

Pearce's Travel Needs Model (Goeldner & Ritchie 2009) exemplifies a hierarchy of travel motivations. All individuals – with and without disabilities – travel to meet a variety of objectives, which are outlined in Figure 1.

*<Insert Figure 1 here about here>*

This model is applicable to the current line of research in that it provides a framework for defining and researching the needs and motivations of travelers. Levels of need outlined in Pearce's model include: physiological needs (e.g., availability of medical and food services); safety and security needs (e.g., window locks on rooms to help ensure that a child will not wander away); relationship needs, which can be enhanced by spending time with faraway relatives or learning about others through travel; and fulfillment needs, which are illustrated by family members' reflections on the effects of travel on their developmentally disabled loved one. This model will also be useful in future research, providing a framework for studying adaptations within the tourism industry as the industry attempts to understand and meet the various needs of consumers with developmental disabilities.

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## 2.0 Method

### 2.1 Study Site

Data for this study were collected in August 2010 at a two-day international conference for family members of individuals with developmental disabilities.

### 2.2 Sampling

The population of interest for this exploratory study was conference attendees who had experience traveling with family members who have developmental disabilities. All conference attendees who were at least 18 years old and who had family members with developmental disabilities were eligible to participate in the focus group component of this study. A sign-up sheet was located in the conference resources room, where many attendees congregated during session breaks. Conference attendees were made aware of the interview sign-up sheet via two formal announcements from the researcher as well as the conference organizer (during lunch and dinner on the first day of the conference). In addition, paper and pencil questionnaires were included in the welcome bags of all conference attendees. Information about the focus group was included in the printed questionnaire.

### 2.3 Data Collection

A small-group interview was conducted following the first day's programming at the two-day conference. The interview was audio recorded, and only those participants who consented to the taping were eligible to participate. A semi-structured interview format was used where both researchers co-facilitated a small group interview and collected field notes over a 90-minute session. Interview questions included the following: 1) Do you travel with your family member who has a developmental disability? If so, how often and to what types of destinations? 2) How do you prepare for a trip with your family member with respect to his/her disability? 3) What challenges have you faced while traveling with your family member who has a developmental disability? Please use specific examples if possible. 4) What are some of the most memorable travel experiences you have had traveling with your family, both positive and negative? What do these experiences and memories mean to you? 5) How do you think the tourism industry (such as hotels, airlines, and attractions) can provide better services to families of individuals with developmental disabilities? In other words, if you could make any changes to the way the travel industry provides services to you and your family, what would they be? 6) Are there other important issues for families of individuals with developmental disabilities that we haven't yet covered?

In addition to the focus group, a pencil-and-paper questionnaire was distributed to all conference attendees in their conference welcome bags. This questionnaire was developed by the researchers based on a review of the related literature and the expertise of the researchers. The questionnaire was to be completed at the respondent's convenience during the two-day conference and returned to the conference registration desk (into a designated envelope) or by mail.

## 3.0 Results

The small group interview ( $n = 4$ ) provided a rich source of information which both supported and enhanced the results of the survey and provided direction for future research in this area. Informants included two mothers and two sisters of individuals with developmental disabilities. Key themes that emerged included preparations for travel, family members' responses to travel, and family needs when traveling. Data provided by one of the four informants was not relevant to the travel-related themes chosen for this manuscript. Accordingly, only three participants are represented in the results and discussion.

**Preparations:** There are many considerations included in the Preparations theme from the most basic levels of need in Pearce's Travel Needs Model (Goeldner & Ritchie 2009). Anticipated responses such as providing for medical, dietary, and safety needs while traveling were discussed. Jane, a sister of an adult with mental retardation, stated: "If I ever took him somewhere while he was depressed, I'd have to make sure...[to bring] diapers. I've never done any of that...I guess I'd have to anticipate either bringing somebody along or training myself...because he'd need bathing...when he's depressed." These preparations may require significant alteration from the norm due to the unique needs of the individual with a developmental disability. For example, families may need flexibility in travel plans in case the stimulation of travel leads to behavior problems, or they may need to find hotel rooms with locks on the windows so that a child on the Autism Spectrum cannot wander off while the family sleeps at night. Often, there is a recovery period after travel where the individual – and the family – ease back into the comfortable patterns of daily life. The post-trip period can be accompanied by changes in the ability to cope, along with behavioral and physical changes associated with high levels of anxiety. As a result, the return home is often an important aspect of the preparation for travel. Sarah, a mother of a child on the Autism Spectrum, described her preparation concerns as follows: "...anticipating his needs and, not just his clothing, but his meds and, you know, [it] really gets thrown off, so that he has bowel problems and it'll take about a week for him to recover after he travels."

**Response:** The Response theme provided insight into the way the individual with a developmental disability responds to cues in the environment related to travel experiences. Activities such as waiting in line, riding or sitting for long periods of time, and loud noises which may barely be noticed by typical travelers can be highly stimulating and can provide a degree of unpredictability and insecurity for individuals with developmental disabilities. These disruptions can result in difficult behaviors,

often in public. Sarah, whose son is on the Autism Spectrum, described his reaction to standing in long lines at the airport: "Standing in line...he just goes nuts if he has to wait too long, he starts to want to push and shove and his language gets terrible...it's not pretty." This aspect of travel clearly shows the variation in safety/security and other needs reflected in Pearce's Travel Needs Model (Goeldner & Ritchie 2009). Sarah's concern about her son's ability to tolerate travel contrasts with Jane's comments about the healing effect of travel she witnessed in her brother, who is an adult with mental retardation: "Sometimes he comes out of it when we go there [to visit family], seeing different faces...I think [travel]'s very therapeutic for him." Jane's brother's response is also reflective of the Travel Needs Model, representing the highest-order need of self-actualization. Jane was not alone in her feeling that travel has a beneficial effect; the other members of the group also felt the same with regards to their loved ones. Although not unexpected, this therapeutic effect demonstrates the value of travel for individuals with developmental disabilities and their families.

Needs: The Needs theme focused mainly on the physiological, safety/security, and relationship needs levels of Pearce's Travel Needs Model (Goeldner & Ritchie 2009). During the interview, family members provided a "wish list" of travel services that they felt would enhance their travel experiences and provide them with access to products and services that would help them ensure that safety, security, and other basic needs are met while they are away from home. One suggestion was for improved hotel websites that would allow them to get to know the hotel better before visiting. "I think that their website should definitely spell out any services or accommodations that they make for people with disabilities beforehand" (Marie, mother of a child with Down Syndrome). According to Marie, this service allowed her to ensure that there were few surprises once they arrived at their travel destination. Another suggestion that was overwhelmingly supported by the group was the need for family bathrooms equipped with changing tables. Marie provided a description of her experiences when family bathrooms were not available while travelling with her son with Down Syndrome: "Changing tables inside those [family] bathrooms...there were times I had to go lay down paper towels in the bathroom...on the floor to change [him]."

In the survey component of the study, participants ( $n = 13$ ) were asked a variety of questions about their travel behavior when traveling with their family members who have developmental disabilities. One closed-ended question participants responded to was, "How do you feel when you think about traveling with your family member who has a developmental disability? Please check all that apply." Results for the seven response options included: excited ( $n = 7$ ), anxious ( $n = 7$ ), stressed ( $n = 5$ ), nervous ( $n = 5$ ), competent ( $n = 3$ ), worried ( $n = 3$ ), and confident ( $n = 2$ ). Additional write-in responses included: "organized" ( $n = 1$ ), "distracted / disorganized" ( $n = 1$ ), and "annoyed by lack of understanding" ( $n = 1$ ). These data supported the data obtained in the small group interview and provided guidance for revising the survey instrument for future use.

#### 4.0 Discussion

Results of this preliminary research suggest that individuals with developmental disabilities and their families do travel for leisure and use tourism facilities and services, including overnight accommodations, attractions, and air travel. Participants identified specific important needs that they felt should be addressed by the tourism industry. Participants identified isolated attempts by the tourism industry to meet their needs, and this initial effort was valued. However, further progress is required in order to help tourism be a tool for self-actualization for this population.

According to Sarah, "[Our children need to learn to function] not just in their community, they have to be able to function in other communities, and in situations out of their norm, so...[travel is] good for that, it's good for the community and it's good for the parents." During the NERR poster session where this research was presented, one symposium attendee expressed surprise about this finding that travel has a therapeutic value not just for the individual with a developmental disability, but to the greater community. Other comments shared by NERR poster session attendees included: a suggestion to investigate the potential therapeutic effect of parks and open spaces as one component of the tourism system; a question about differences in travel patterns between single-parent and dual-parent households; an inquiry about the availability of training and certification programs for tourism industry professionals; and an observation that resources and support are available for group travel for individuals with developmental disabilities, but not for families traveling independently. Finally, one conference attendee shared that she had a child with a disability, and that she had observed that the travel experiences she felt went poorly were the ones her child enjoyed the most.

These findings provide a basis for continuing this line of research. Suggestions for future research include: revision of the survey instrument and redistribution on a larger scale, assessment of the tourism industry's knowledge and preparedness to provide services to individuals with developmental disabilities, and development of an action plan to involve and educate tourism service providers.

#### 5.0 Citations

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Figure 1: Pearce's Travel Needs Model (Goeldner & Ritchie 2009)

