

The Camping Experience Among Families Who Have a Child with a Disability¹

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Abstract: The purposes of this study were to investigate how families who have a child with Down's syndrome spend their vacations and to explore families perceived barriers to family vacations. Interviews were conducted with families who had at least three children, one of whom had Down's syndrome. Using qualitative methods, data were collected in an exploratory study (n=25). An analysis of the results explores family vacation preferences and factors affecting family camping experiences.

The purposes of this qualitative exploratory study were twofold: (a) to investigate how families who have a child with Down's syndrome spend their vacations and (b) to explore families perceived barriers to family vacations.

A review of literature exploring family leisure research and more specifically, family vacations among families who have a child with a disability was conducted. Research has been extensive in the areas of leisure and family as separate entities, however few studies have been conducted on the role of leisure within the family. Some of the research reviewed for this study was found in the disciplines of family systems, leisure, and sociology (e.g., Holman and Epperson 1984; Murphy 1982; Rosenblatt and Russell 1975; Lucca and Settles 1981; Lyons 1987; Orthner and Mancini 1980, 1990). The literature dealing directly with vacationing for the disabled and their families was found to be scarce.

Methodology

To investigate family vacation patterns and perceived barriers to vacations, a multiple case study was conducted. This study was of an exploratory nature, and was intended for heuristic rather than prescriptive purposes.

Subjects for this study included 25 families who met the following criteria: (a) each family had a child with Down's syndrome, (b) each family had at least three children, (c) each family resided in a rural setting within 200 miles of Chico, California, (d) the parents were married and lived together, (e) at least one parent was employed full-time, and (f) both parents had earned a high school diploma. A purposive sample was used. The selection process was not necessarily intended to produce a representative sample of families who had a child with Down's syndrome living in California. However, the sampling process did assure that the families who were interviewed met the study criteria.

Because a wide variety of behavioral patterns are associated with Down's syndrome, a behavioral profile for the children with Down's syndrome was developed to further limit variance among the families.

A triangulated approach was used in the collection of data: (a) in-depth interviews were conducted and audio-taped, (b) field notes were taken during each interview, and (c) the responses and notes were reviewed by the subjects to verify accuracy and validity.

In the spring of 1990 all special education directors of rural counties within the study area (Northern California north of Stockton) were contacted and the purpose of the study was described. Of the 24 county special education directors contacted, 18 agreed to participate in the study. The investigator sent letters of invitation to the directors who in turn routed them to teachers of children with Down's syndrome. The teachers distributed the letters to families who met the characteristics for inclusion in this study. The families in turn contacted the investigator.

Interviews were scheduled with the entire family present and were conducted in the homes of the families. The data collection period lasted 1 week per two families for a total of 10 weeks.

Results and Discussion

Camping was identified as the favorite family vacation among most families. Camping vacations were viewed positively by family members and described as opportunities to build family cohesion, enhance communication, and relieve stress. Nearly all of the families who camped spent their camping vacations in California. All of the responding family members stated that they would like to camp more. Factors affecting the family camping experience included time constraints, location of family vacations, lack of recreational opportunities at camp grounds, and physical and/or behavioral problems experienced by the child with Down's syndrome. In most cases (72 pct of families) the presence of a child with Down's syndrome did not significantly alter family camping experiences. Seven of the families, however, exhibited extreme adjustments based primarily on the severity of physical complications and behavioral problems associated with Down's syndrome. The data suggest that those families who had a child with Down's syndrome who experienced physical and/or behavioral problems limit themselves to the home environment as their primary location of family leisure and vacations.

Several implications, based on the data and on the investigator's observations, are offered to enhance the camping experience for families who have a child with a disability. Every

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effort should be made to make campgrounds as accessible as possible. This means that all common facilities and an appropriate percentage of campsites should be accessible (Americans with Disabilities Act, 1990). This allows for more individuals and their families to access federal, state, and local park systems. Accessible restrooms, drinking fountains, telephones, gradual slopes, and appropriate signage denoting facilities and trails should be a consideration when planning campgrounds.

Respite care is a service which provides parents a temporary cessation of childcare. Families who have a child with a disability would be much more likely to camp if opportunities for respite care were available. Although it is probably beyond the scope of campgrounds to provide this service, park personnel can encourage the private sector to offer respite care during peak seasons. In addition, lists of care providers can be made available to those families with special childcare needs. Staff should be trained to accommodate children with special needs. Such training would not need to be extensive but would include in-service workshops designed to train employees how to recognize and meet the unique needs of individuals with disabilities.

Some children with disabilities lack sufficient judgement in environments which may have possible hazards. When environments which pose minimal threats to personal safety are fostered, parents can feel relaxed about their children playing in safe areas. Elements of a safe environment that were commonly

requested by parents were proper supervision, trained staff, and accessible programs.

These are some suggestions for enhancing the camping experience of families who have a child with a disability. It is clear from the data that park service professionals and other natural resource managers face challenging opportunities in providing for this under-served user group.

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