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BENEFITS AND COMPONENTS OF AN INCLUSIVE ADVENTURE PROGRAM FOR FAMILIES WITH CHILDREN WHO HAVE A DISABILITY

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Approximately 20.3 million families have a member with a disability in the U.S. In addition, 3.8 million families have at least one child with a disability (LaPlante, Carlson, Kaye, & Bradsher, 1996). Due to the national movement in the 1970s to deinstitutionalize individuals with disabilities, the vast majority of these children live with their families in community settings; however, the recreation opportunities for these families to participate together in community sponsored programs may be limited. There are many programs for children with disabilities, but few are designed for the entire family when one or more children have a disability. Shifting the focus from the individual with the disability to the entire family can support and enrich the intrinsic strengths that already exist in the family (Clapp & Rudolph, 1993; Dunst, Trivette, Starnes, Hamby & Gordon, 1993; Lakin, 1998; Turnbull & Turnbull, 1997), which can create pathways toward the social inclusion of the family to the greater community. Family support and community human service programs are recognizing this and beginning to recommend incorporating inclusive, family-centered recreation opportunities for the entire family into community program philosophy and practice (Dunst, et al., 1993; Lakin, 1998; Orthner, 1998). The purpose of this research was to identify the benefits and components of an inclusive family outdoor recreation program. The participating families in this study identified the programmatic components that contributed to their successful involvement.

Family recreation is highly valued in many American families. Holidays, family outings, church activities or simply shared time together is considered important to healthy family life. Participating together in leisure activities enables a family to gain new skills, strengthen family bonds, and network with other families and the community for additional information

and support (Kelly & Kelly, 1994; Mactavish, 1994; Orthner, 1998). Susan Shaw (1999) interviewed families without disabilities and generated themes on parents' view of family leisure. Parents viewed leisure as having a specific purpose for the family unit. During family leisure, parents specifically strove for family activities that promote: a) family communication and bonding to share values and traditions, b) child development and learning opportunities, and c) the enjoyment of lifelong health and fitness. These themes are also important for families that include a child with a disability, and family outdoor adventure and camping can provide these outcomes for the entire family.

Having entered the 21st century, there is an increasing demand for recreation providers to accommodate the social inclusion of our community members with disabilities (Dunst, et al., 1993; McAvoy & Lais, 1999; Schleien, Ray, & Green, 1997; Turnbull & Turnbull, 1997). When addressing children with disabilities, the family represents an underutilized component when designing inclusive recreation services (Lakin, 1998; Orthner, 1998). In many situations, it is the family that sustains the social infrastructure and quality of life for most individuals with disabilities, whether physical, mental, or developmental (Singer, 1996). All families seek integration into the community, but families that include a child with a disability sometimes have unique challenges. Depending on the nature of a family member's disability, the role of recreation may be "expanded, unaffected, or curtailed" (Turnbull & Turnbull, 1997, p. 124) for the family as a whole. Consequently, these families may experience reduced social and leisure opportunities (LaPlante, et al., 1996; Levy, 1985).

In a study investigating the nature, benefits of, and constraints on family recreation in families that included children with developmental disabilities, Mactavish (1994) found that family

recreation might be the only option for the member with a disability. A greater emphasis was placed on family recreation experiences if the parent(s) perceived that the child(ren) with a disability were unlikely to experience lasting interpersonal relationships and meaningful recreation involvement outside the family unit. Family recreation ensured that the member with a disability had recreation opportunities that were "positive, supportive and enduring interactions with nondisabled family members" (Mactavish, 1994, p.164).

Although family recreation can produce stress and conflict (Shaw, 1997), the benefits derived from family leisure can be more influential than the negative experiences (Orthner, 1998). However, families that have a child with a disability have difficulty with: a) finding activities that are flexible enough to accommodate a wide range of abilities, b) a limited amount of information available about family recreation options, and c) the planning demands necessary to accommodate a member with a disability. Otherwise, constraints on family recreation participation have many similarities as non-disabled families (Mactavish, 1994).

Through inclusive family recreation, community agencies can enhance a child's full integration into his or her family and community life. Powers, Singer, and Todis (1996) investigated the "key childhood experiences of people with disabilities who grew up to be successful adults with positive self-perceptions" (p. 71). An important theme associated with family cohesion and positive child-rearing outcomes was the inclusion of these children in typical recreation activities and leisure experiences. Family recreation opportunities may also help extend the social relationships of children and youth with disabilities beyond parents and siblings and offer a positive benefit for the entire community (Heyne, Schleien & McAvoy, 1993; Lakin, 1998; Schleien, Ray & Green, 1997).

In considering the design of outdoor recreation programs for families, it is critical to understand families as an interactive and dynamic system. As a result of viewing the family as a whole system and not only by its components (Bronfenbrenner, 1979; Whitechurch & Constantine, 1993), innovative family service

delivery models can be considered. The family consists of the sum of its members' mutual and reciprocal perceptions and interactions. Inclusive family recreation is an inter-subjective experience that occurs between family members, contributing to social connection and cooperation. Providers of recreation services need a better understanding of the needs, desires and abilities of all families to better serve the community (Orthner, 1998). With imagination and education, outdoor recreation programs can extend this value to include families that have a child with a disability.

PROCEDURES

This study was designed to identify the programmatic components necessary for families that include a child with a disability to participate together in a comprehensive outdoor recreation program. Two primary organizations developed a family outdoor program in partnership: Wilderness Inquiry (WI) and Parent Advocacy Coalition for Educational Rights (PACER), both located in Minneapolis, MN. Wilderness Inquiry, a non-profit outdoor adventure organization, provides integrated outdoor education and recreation opportunities for individuals with and without disabilities. PACER, also a non-profit organization, advocates on behalf of persons with disabilities and their families. These organizations collaborated to offer a family-oriented program called Project FIT (Families Integrating Together).

Participants in this study were: a) Minnesota families that have one or more children with a disability; b) recruited from a pool of applications distributed by PACER; and c) selected by the PACER project coordinator and the Project FIT educator from WI. A completed application by an interested family did not automatically ensure selection for Project FIT. Families were selected based primarily on family commitment, need for the service provided, and enthusiasm for the project.

Ten families participated in Project FIT over an 8-month period. Program activities included: a) 20 hours of outdoor skills training and trip planning conducted over 4 sessions (see Table 1); b) a three- to six-day integrated outdoor

adventure for families with and without disabilities; and, c) opportunities for families to share common interests and provide mutual support for the families' pursuit of outdoor activities. Participating families varied in configuration

and included children with a variety of disabilities (see Table 2). These particular variations provided themes and commonalities about all participating families.

TABLE 1
Family Training Sessions

Session #1:	Introduction to Project FIT and WI's Program Participation Model (McAvoy & Lais, 1999). Families discussed particular goals/concerns/barriers to family outdoor recreation participation.
Session #2:	Family tent set-up & fire building instruction. At this session, families also receive information about extended family vacations with WI for their family to consider in relation to their family's goals and abilities.
Session #3:	Camp cooking, low-impact camping lesson, and an opportunity for families to test possible adaptive equipment for hiking. Scheduling for extended family vacations occurred between Session #2 and Session #3. Discussion about trip itinerary and considerations, natural and cultural history, and safety issues related to family trips.
Session #4:	Canoe Participation with family at a WI canoe event. Session curriculum included canoe safety and paddling skills. Families also use this session to familiarize themselves and test various adaptive equipment for canoeing.

TABLE 2
Configuration of Participating Families

Family	# of parents in the home	Disability of child	Age of child w/disability	Age of Siblings w/o disability
A	1	Autism	12	-
B	2	Cerebral Palsy	8	8, 12
C	2	Spinal Cord Injury	10	1, 6, 11
		ADHD	8	1, 6, 11
D	2	Cerebral Palsy	5	6, 8
E	2	Cerebral Palsy	8	6, 8
F	2	Cerebral Palsy	8	8
G	2	Cerebral Palsy	27	20
		Tourette's	16	20
H	2	Brain Injury	22	16
I	1	Manic Depression	14	13
J	1	Cerebral Palsy	13	10

BENEFITS AND COMPONENTS OF INCLUSIVE ADVENTURE

TABLE 3

Primary Data Collection Schedule

	March 1999	June-August 1999	July-September 1999	October 1999	January 2000
Individual Family Interview Schedule	Initial interview after Training Session #1	Telephone interview 1 week before family vacation	Interview 2 weeks after extended family vacation		Follow-up interview 3 months after Family Outdoor Program
Focus Group Interview				Focus group interview	

Extended Family Vacation

With guidance from the Project FIT educator, families selected an extended outdoor recreation adventure based on individual family goals, family ability, and availability of family trips offered by WI. The trips took place between June and September, 1999. Most participating Project FIT families did not participate on the same extended trip as other the Project FIT families. Each family integrated into regularly scheduled WI family trips as advertised in the 1999 catalog for their extended outdoor vacation. The trip options for Project FIT families were:

- Itasca State Park Family Adventure (4-day trip car camping in Minnesota)
- St. Croix River Family Canoe (3-day canoe trip in Minnesota)
- Voyageurs National Park Family Canoe (5-day canoe trip in Minnesota)
- Yellowstone National Park Family Adventure (6-day car camping trip in Wyoming)

Data Collection

One researcher conducted this study with the assistance from an evaluator of Project FIT hired from the University of Minnesota by WI. The data collection methods included: a) four individual family interviews, and b) one focus group session with participating families (See Table 3). Data sources were a) adult family members and b) their children with and without disabilities.

Interviews

Collecting interview data consisted of two face-to-face interviews and two telephone interviews with each family. Valle and Halling (1989) suggested that personal interviews aid in a more accurate description of the experience, rather than a survey or questionnaire. The goal of interviewing each family was to obtain a rich description of their recreation experiences as a family unit.

An initial interview took place with each participating family at the onset of the WI family training sessions. The interviewer asked families about the context of family recreation in their everyday lives. Sample questions include "What is the family recreation experience like when one members has a disability?" and "Are there challenges?"

A telephone interview with the parent(s) occurred one week before the family participated on an extended family vacation with Wilderness Inquiry. This interview asked the parent(s) about the value of the training sessions and about the family goals for the planned outdoor trip.

A third family interview took place approximately two weeks after completing a three-to six-day WI outdoor adventure. This interview asked the family about their experience on the trip, effects of the trip since the family returned home, and any future recommendations the family members has for family outdoor adventure programming.

A final telephone interview took place three months after the families completed the entire outdoor family program. This telephone interview asked families about their recent family recreation activities since participating in Project FIT program and their potential family recreation plans for the coming summer.

Focus Group

Family members took part in a semi-structured focus group that lasted approximately 60 minutes to discuss important program components that enhance family-based outdoor recreation activities and those factors that contribute to community-based family support programs. For example, participating families were asked, "What situations make outdoor recreation opportunities accessible for families that include a child with a disability?"

Focus groups took place at a scheduled meeting place convenient for all focus group participants. Halfway through the meeting, families were divided into a children's group and a parents' group. In this way, the researchers explored different perspectives among family members, those of adults and of the children. Focus group protocols followed Kruger's (1994) focus group methods.

All interviews were audio-recorded and transcribed by the researcher for analysis to establish themes regarding whole-family recreation experience. The researcher established essential patterns or invariant meanings, keeping the description intact and in context. The researcher reviewed all interviews. The external evaluator for Project FIT, a staff member of the University of Minnesota's Institute on Community Integration, separately reviewed the interview data to achieve a high level of inter-rater reliability. This second individual assisted in identifying themes and patterns within the transcribed interviews. Qualitative data analysis methods included the organization of all interviews reduced into multiple categories by data coding, sorting and indexing to establish essential themes and patterns.

FINDINGS

Family Benefits

The primary purpose of this paper is to report on the program components that contributed to successful inclusive family outdoor programming. However, the study also documented some of the benefits families gained from these whole family programs. The qualitative interviews revealed that participating families benefited from the program by an increase in their knowledge and confidence as a family unit (see Table 4).

First, the training sessions helped to decrease fears about camping. Parents were able to test how outdoor activities could work for their family, and their children could anticipate what to expect. This helped parents to feel more optimistic before embarking on a multi-day adventure. For some families, the graduated challenges of the training meant choosing a shorter, less remote trip than they originally envisioned. A surprised father commented on how appropriate a car camping trip to Itasca State Park was for his family.

Dad: I think honestly, we were probably thinking of ourselves at that point more than the kids. We knew that Yellowstone was foolhardy, but then Itasca was really the other end of the spectrum. It seemed so close. It seemed so simple. Surprisingly, Itasca turned out well.

Most families came home from the extended trip with an enhanced sense of confidence. The sentiment was "We did it; we could do it again; and perhaps, even do it on our own." Following participation in the program, one mother, Brigitte, reported she had attempted more outings to local parks with her son who has autism.

I am going to try this weekend and see if we can go further than our one-hour radius around our home. I am going to try and push it just a little bit further. Prior to the [WI] trip, we really avoided that [going to

TABLE 4
Benefits to Participating Families

Benefits	Description
Increased knowledge and confidence as a family unit	<ul style="list-style-type: none"> • Training alleviated fears of both parents and children. • Increased confidence to try shorter outings independently. • Parents increased awareness of child's abilities. • Family members learned practical ways to safely integrate child into outdoor recreation activities.

parks if there were very many other people]. I had been wanting to try it, but I had absolutely no idea how to even begin.

This "We can do it" attitude also increased confidence in planning family outings unrelated to outdoor recreation, such as a trip to Disney World or the local zoo. Parents also indicated an increased awareness of their child's physical and social abilities. Brigitte continues to describe her experience:

I was not expecting him to tolerate it as well as he did. I learned that he can tolerate more people than I had thought he could tolerate being around. I was able to see when his behavior was task avoidance and when he was not ready or bothered.

Many families were surprised to learn they could manage their child with disabilities in an outdoor setting. This was especially important for one family who had a long history of participation in outdoor recreation activities but stopped when their daughter incurred a spinal cord injury. Project FIT taught them practical ways for their daughter to be active in the family's previous activities, while assuring her safety. These strategies included closely monitoring the amount of time she was in the water if swimming in a cold lake and techniques to keep her warm at night when sleeping outdoors.

Program Issues that Contribute to Family Success

Practitioners must better understand their current level of effectiveness, their capacity for flexibility and accommodation, and the opportunities for whole family involvement in recrea-

tion. This includes not only increasing the child with a disability's involvement in family activities but also increase the range of possibility for a vacation for the entire family. The families participating in this study identified the following five issues as the key elements of program design that contributed to successful whole-family participation: 1) careful attention to safety; 2) appropriate but real challenge for families; 3) opportunities for socialization among all family members; 4) a balance of group and individual activities; and 5) qualified staff to provide technical and personal support to families (see Table 5).

First, families who participated in this program valued instruction in basic outdoor and safety skills. They also valued trip leaders who were able to openly discuss special considerations related to various disability issues and emergency contingency plans before going on an extended trip. Parents asked and needed answers to questions such as: "What if something happens to Ann when we are in Yellowstone? Where are the closest medical facilities?" "Would a portable generator be allowed for nebulizer treatments for Jerry's asthma?" One mother shared her concerns about her family's ability to participate in Project FIT:

When I heard that we were going to places that were more remote than a campground, I really doubted our participation.... After our first meeting, I felt like there were enough choices so we could stay in [the program], but we had to be careful with what we chose.

Second, families wanted appropriate but real challenge. They specifically wanted hands-on

TABLE 5

Key Elements of Program Design that Contributed to Whole-Family Participation

Program Issue	Description
1. Careful attention to safety	<ul style="list-style-type: none"> • Openly discuss safety concerns, disability issues and emergency contingency plans • General and specific supervision needs • Teach outdoor safety skills to all family members
2. Appropriate but real challenge	<ul style="list-style-type: none"> • Identify ways to include all members to the fullest extent possible
3. Opportunities for socialization	<ul style="list-style-type: none"> • Group and peer interaction • Interaction of families with and without disabilities • Age appropriate activities for parents, adolescents and children
4. A balance of group and individual activities	<ul style="list-style-type: none"> • Make it “easy” for parents to participate • Options to engage in alternative or individualized activities when necessary
5. Qualified staff to provide technical and personal support to families	<ul style="list-style-type: none"> • Manage disability issues in the outdoors • Communicate itinerary information that effects daily living needs and adaptive issues • Provide personal care attendants liberally

experience to identify methods that engage all members to the fullest extent possible. Parents valued the opportunities they received during the training sessions to test simple adaptations for hiking and canoeing. Jim, an eight-year-old with cerebral palsy, and his family learned to use the insert from his wheelchair to participate comfortably in a canoe outing. Using the insert enabled Jim to sit upright, hold a paddle, and participate to the fullest extent possible. As an alternative, Mike (another eight-year-old with cerebral palsy) was able to use his car seat to get similar results. Providing these experiences with simple modifications enabled the families to consider a wider range of activities than they had been doing, especially in the outdoors.

Third, parents wanted the outdoor trips to provide opportunities for socialization for all family members. Trip leaders employed various activities to encourage group interaction, peer interaction and interaction between families with and without disabilities. One parent of a child with significant disabilities was gratified when

another parent whose child did not have a disability thanked her for bringing her son on the multi-day trip. For this parent, the “Thank you” meant “that her family had learned from ours and that made me feel very good.” Parents also expressed that peer interaction was not only important for their children but beneficial for themselves, as well. Depending on the demand of care giving, parents may have limited opportunities for socializing in their everyday lives. There was no evidence that the families who participated together in the training continued to develop an ongoing relationship beyond the program. However, a few families did express some interest in establishing such connections in the future.

In addition to socializing, parents said that all family members were engaged when there was a variety of age appropriate activities. Younger children enjoyed group games and teenagers enjoyed activities that were physically challenging. It is important to offer alternative or individualized options for families when an ac-

tivity is not working well for their child. Some families need the flexibility to leave and then reenter the group easily in order to manage disability or parenting issues in the outdoors without being concerned with "holding up the group." Many parents found it practical to take their own vehicle when going on the outdoor adventure. This provided them with the option to leave the group early or perhaps for a short time, if they need to improvise away from the group.

The fourth indicator is finding the right balance of activities that make it "easy" for parents to participate. This means providing necessary equipment, extra child supervision, providing meals, and social activities. These options offer more opportunity for family leisure experiences. In the absence of such support, parents are less likely to consider participating in an outdoor adventure, because they anticipate much work, effort and potential stress. Being part of a larger group was a particular relief for single mothers. They could not imagine attempting an extended outdoor adventure on their own without assistance of others due to tasks such as cooking while also watching and supporting their children.

Finally, parents need to feel comfortable that the outdoor recreation providers have competent and well-qualified trip leaders. Parents of children with disabilities need outdoor recreation leaders not only to provide technical support but also to pay attention to personal needs of all family members. Trip leaders need to communicate important information frequently in relation to the outdoor itinerary and the disability needs or adaptive issues.

There will also be situations when personal care attendants (PCA) will be appropriate. The need for a PCA is frequently considered necessary depending on the functional limitations of the individual with a disability (McAvoy & Lais, 1999) and should be considered when providing inclusive family outdoor programming. Providing personal care attendants has the potential to create an environment for families to participate in a fuller range of integrated outdoor experiences. Some families in this study elected not to bring a personal care attendant along on their trip and found it more difficult than they had anticipated. It meant that parents sometimes

missed opportunities to spend time with their children who did not have disabilities or had limited opportunities to socialize with adults on the trip. One parent noted that the lack of a personal care attendant prevented her son with a disability from playing with other kids during times when parents were busy with camping tasks such as preparing meals or packing gear. On the other hand, a personal care attendant enabled other parents to feel comfortable enough to have a more enjoyable experience than they might have had otherwise. In discussing challenges during typical family outings, these parents illustrated how having a PCA available was helpful to assist their son with disabilities:

Dad: If it is just us when we are in public, there is a lot of stuff to do and all our kids are excited. We want to do stuff with them but the only outlet for taking care of Daniel is one of us. Then our stress level will tend to go up.

Mom: Then the person who is not sitting on the bench in the heat holding Daniel feels bad that the other one is there and feels a little bit guilty.

Dad: The one who is in the water with the other two kids thinks, "Boy, I got to get back and relieve the other one." When you have Mary [PCA] then we can both do stuff.

Mom: It is nice to have that option.

Dad: So, you feel better about enjoying the whole experience rather than always having to think, "Is Daniel all right?" We can transfer some of that for a little while, knowing that he is all right.

CONCLUSION

Innovative outdoor recreation programming can extend a hand to parents interested in assisting their children and youth with disabilities to develop and grow, while also maintaining a high quality of life for the entire family. However, outdoor recreation programmers must recognize the challenges encountered in this study. The most prominent challenge was getting these families to enroll in the program. It had not oc-

curred to these parents that they could consider camping and outdoor adventure with their child with a disability. One family did drop out of the program after the second session, deciding it was a bigger commitment and greater risk than they were willing to take. The most effective method to get families to consider Project FIT and commit to participating to the entire program was to solicit testimonials from past participants to recount their experience. Parents needed assurance that the program had worked for other families. Past participating families who attended the second training session, and organization newsletter articles about a family's experience, helped accomplish this. Parents trusted the recommendations of other parents over recommendation of professionals.

A second challenge was to develop the training sessions that matched a variety of capabilities and interests. The trainings required a programmatic design that encompassed a range of ages and abilities (e.g. a parent, a 10-year-old with a spinal cord injury, and a 8-year-old with ADHD).

The third challenge of providing an inclusive outdoor adventure was in helping the families determine their support needs, once they began to set their family goals and consider an appropriate family vacation. Families were more familiar with support needs in their home environment but needed help to identify and minimize potential risks without eliminating the activity's challenge and enjoyment. Parents looked toward the recreation professional to learn from their expertise and experience.

Having a child with a disability does not have to preclude a family from taking an outdoor trip together. Family-centered outdoor recreation programs can enhance the perceived well-being of the family, offer opportunities for self-discovery and create pathways towards social inclusion. However, further research in supportive programming strategies and innovation in adaptive equipment will enable recreation providers to effectively design inclusive outdoor adventures that are realistic leisure options for these families. Effective inclusive outdoor recreation has the potential to bring families that include a child with a disability a sense of ac-

complishment, confidence and adventure that they may not have known possible.

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