

REGULAR PAPER

## Parent Perspectives of Barriers to Child Participation in Recreational Activities

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### Abstract

Parents who have sons and daughters with disabilities usually have significant influences on their children's play, community participation, socialization, and overall quality of life. For several decades, parent-professional partnerships have been considered a recommended practice toward effective service provision for children with disabilities (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). Since parents know their children best and have much to share with service providers, it is essential that parents and professionals communicate often and clearly as programs and services are designed and implemented. In the current study, five focus groups were established to learn how parents feel about recreation service delivery systems, to provide a format to have them share their concerns, and inform us about what has been effective regarding their children's community inclusion. Focus groups offered parents a platform to voice concerns about opportunities for their children with intellectual and related developmental disabilities to successfully participate in recreation and social activities. Parents valued community recreation as an important aspect of their children's quality of life; however, they were distraught by the ongoing battle for access. Continually being required to provide direct supports to their children because program staff would not, along with negative attitudes of community members, left them fatigued and isolated. Parents had concerns for their children's safety and well-being due to poorly prepared program staff. Emanating from these focus groups was an understanding that family members and advocacy agencies have much to offer recreation providers in facilitating inclusive programming, but ultimately, recreation providers are responsible for meeting the needs of all children.

### Keywords

*community recreation; families; family-professional partnerships; focus groups; inclusion; intellectual and developmental disabilities*

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## Introduction

It has been effectively argued from an equal rights standpoint that all people deserve to be valued socially by being included in typical places and activities with their peers. Taking a pragmatic approach, a large majority of people with disabilities now live in the community and have interests and needs to participate there. Specifically, recreational participation with one's peers in the community assists with making and nurturing friendships, helps develop age-appropriate skills, provides appropriate channels for choice-making and self-determination, and helps establish a more fulfilling lifestyle (Bullock, Mahon, & Killingsworth, 2010). Individuals who are denied these inclusive opportunities generally have more limited skill repertoires, smaller social networks, and make fewer choices (McKnight & Block, 2010). Moreover, by including people with disabilities in typical recreation programs, participants with disabilities and the entire community reap the benefits. Through first-hand exposure to and ongoing interaction with people of varying abilities, community members gain knowledge about individual differences, become more empathetic and sensitive to the needs of others, develop more accepting attitudes, and broaden their own opportunities for friendship (Schleien, Ray, & Green, 1997).

Knowledge about the design of inclusive recreation programs and best practices that support them continue to be developed and disseminated in the recreation and parks field. Nevertheless, inclusive service delivery has not become standard operating procedure in most recreation agencies (Schleien, Miller, & Shea, 2009). The significance of partnerships in planning is evident in public-policy research and federal legislation. In fact, the concept of parent-professional

partnerships in the design and implementation of special education programs is one of the principles of IDEA (Blue-Banning et al., 2004; Turnbull & Turnbull, 2000). In order to facilitate inclusive services, continuous communication among participants, family members and other advocates, and practitioners must occur. Also, all of these parties must take a shared responsibility approach to help ensure that everyone's recreation and social needs and interests are met (McKnight & Block, 2010). In its absence—when these partnerships and responsibilities are absent, and family members and practitioners do not communicate, trust one another, and work together to eliminate barriers to inclusion—individuals with disabilities continue to have limited access to the broader community. Consequently, our communities continue to pay a hefty price as individuals of varying abilities are denied their citizenship and the kinds of supports and services that would enable them to be accepted and valued community members (Schleien & Miller, 2010; Smith, 2010).

Parents who have children with disabilities, including intellectual and related developmental disabilities (ID/DD), have many ideas about their children's participation in community recreation. As individuals who know their children best, parents could provide valuable information about a child's preferences, personality, abilities, needs, learning styles, and idiosyncrasies. Years of experience have made parents rich sources of recommendations for meeting the needs of their children (Heyne & Schleien, 1994; Miller, Schleien, & Lausier, 2009).

Focus groups and interviews with parents of children with disabilities have consistently identified a number of concerns they face regarding community recreation participation. The lack of op-

opportunities for children to participate in recreation programs, especially those that enable them to participate alongside their peers without disabilities, is pervasive (Emira & Thompson, 2011; Jones, 2003/2004; Thompson & Emira, 2011). Furthermore, a number of external and internal barriers to their participation exist. Prominent environmental barriers identified by parents included a lack of staff awareness, understanding, and training; negative attitudes of program staff and peers without disabilities; and an overemphasis on competitive programming within recreation agencies (Emira & Thompson, 2011; Goodwin, Fitzpatrick, Thurmeier, & Hall, 2006; Jones, 2003/2004; Thompson & Emira, 2011). Internal barriers that were most commonly identified by parents were their children's behavioral and social skill deficits (Goodwin et al., 2006; Jones, 2003/2004) and their own internal turmoil between the perceived safety available in segregated and specialized programming and the desire for their children to be included in general community recreation (Thompson & Emira, 2011).

Based on the understanding that family members' knowledge and perspectives are an essential component of inclusive services, and that few successful programs are designed in their absence, a series of parent focus groups were initiated through a university-community partnership. Focus groups are particularly suited to providing a "voice" for key stakeholders, including parents, by listening to them within the full context of their experience (Sandall, Smith, McLean, & Ramsey, 2002). This article describes the findings of this initiative and delineates specific parental values and perspectives concerning community access, participation, and inclusion. This

study was designed to explore what parents were thinking concerning the current recreation service delivery system, the obstacles that they and their children were confronting, what programs and practices were effective in meeting their needs, and what they wanted recreation professionals to know and do. Suggestions for recreation providers and advocacy agencies are made to more effectively serve people of varying abilities.

## Methods

A focus group format was instigated to further explore how parents with children with ID/DD think and feel about community inclusion. Focus groups recognize participants as experts and allow group interactions that encourage attempts to identify, analyze, and find solutions to problems (Barbour, 2005; Krueger & Casey, 2000).

## Participants

Focus group participants were recruited from the population of families connected with two local advocacy organizations; the local chapters of The Arc and Autism Society. Administrative staff at these agencies identified and contacted families who were receiving agency services, or participating in agency programs, to personally invite them to participate. Interested families were mailed an informational packet including a letter describing the purpose and procedures of the focus group, a list of questions that would be asked, an informed consent form, and that they would receive compensation for their participation. Three to five days prior to the scheduled focus group, the principal investigator telephoned parents to discuss the focus group purpose and procedures, review the consent form, and answer questions.

Five focus groups were conducted within a 9-month period and involved 35 parents of 38 children diagnosed with autism spectrum disorder or ID/DD. Three groups were conducted with families affiliated with The Arc, and two with the Autism Society. Each focus group was designed to obtain data from parents of children at various stages of life. The target age ranges of the represented children were: grades K-8 (ages 5–12), teen/transition-age (ages 13–19 years), and adults (ages 20 and older). However, due to scheduling accommodations, there was some overlapping of represented ages across the groups. Table 1 depicts the characteristics of the focus group participants and their children. After five focus groups, the researchers decided against additional ones as they felt saturation of data relevant to the specific questions had been reached.

### Focus Group Design and Implementation

Focus group discussions were led by two co-moderators (first and third authors) and limited to 90 minutes. Discussions were largely driven by the participants; however, the co-moderators initiated and directed each conversation with six open-ended questions to elicit personal responses and encourage interaction among the participants (see Table 2). At the conclusion of each session, participants were given \$35 as compensation for their time, transportation, etc.

Each focus group was audio-recorded and two trained notetakers recorded relevant quotes from the discussion. Immediately following each focus group, the research team convened to discuss initial impressions, identify themes, and summarize what they learned from the participants (Morgan, 1998). Extensive notes were generated during these debriefings as part of data collection and analysis efforts.

**Table 1**

### *Focus Group Participant and Child Characteristics*

Participant's Relationship to Child	
Mother	77%
Father	23%
Child's Primary Diagnosis	
Autism Spectrum Disorder	58%
Intellectual Disability	37%
Other Developmental Disability	5%
Child's Race/Ethnicity	
White/Caucasian	58%
Black/African American	18%
Hispanic	5%
Bi-racial	5%
Other	3%
Missing	11%
Age Range of Children Represented ( <i>m</i> )	
Focus Group 1	8-15 (11.4 years)
Focus Group 2	12-23 (17.5 years)
Focus Group 3	20-44 (29.6 years)
Focus Group 4	5-12 ( 7.3 years)
Focus Group 5	11-29 (18.4 years)
Number of Participants per Focus Group	
Focus Group 1	8
Focus Group 2	7
Focus Group 3	10
Focus Group 4	5
Focus Group 5	5

Audio and notational data were reviewed multiple times by two research team members and an abridged transcript of the relevant and useful portions was developed (Krueger & Casey, 2000). The abridged transcript was then coded based on the primary questions addressed in the focus groups (i.e., successes, challenges, dreams, concerns/fears, alleviating concerns, recommendations), as well as additional themes identified and discussed in the debriefing sessions (e.g., family isolation, parent fatigue, parent-professional partnerships).

**Table 2**

*Focus Group Questions*

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- Introduce yourself and briefly describe your son's/daughter's recreation and sports interests (ice breaker).
- Describe your child's experiences in community recreation and sports?  
What successes have they experienced?  
What challenges have they encountered?
- What are your dreams and desires for your child's future community participation?
- What are your concerns or fears about your child's participation in inclusive programs alongside peers without disabilities?
- What would it take to alleviate these concerns?
- What recommendations do you have for local recreation providers to improve access and facilitate participation and inclusion for your child?
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A report was generated for each focus group organized around the identified themes with representative quotes, and examined for accuracy by all members of the research team. To increase the trustworthiness of the findings, each participant was provided with a copy of the report from the focus group in which they participated and asked to comment on its accuracy and representativeness.

Once all focus groups had taken place, a process of axial coding was conducted on data in each code. Axial coding involves looking for answers such as why or how come, when, where, how, and with what results; and through this process uncovering relationships within and between codes that contextualize the phenomenon under investigation (Strauss & Corbin, 1998).

### **Findings**

Seven themes arose from the analysis that will be used to organize this presentation of findings. These themes addressed (a) recreation as a valued and important aspect of their child's quality of life, (b) the continuous battle for access

to recreation opportunities, (c) fatigue by having to do it all, (d) experiences of isolation, (e) dreams and desires, (f) internal conflict between desire for inclusion and keeping their child safe, and (g) a clear message to agencies/providers that the current lack of access was unacceptable.

#### **"They Need that Outlet"**

In myriad ways, parents expressed how important recreation was for their children, as it met their physical and social needs, in particular. General statements such as "when it comes to recreation, he needs that; he needs to get out" were very common. Parents valued recreation participation as a way to "maintain physical wellness." As one individual pointed out, "Even though he has autism, he still needs those health benefits. Because when he turns 40, he is still going to have the same genes as the rest of us have in our family." Recreation was also valued for its ability to "alleviate a lot of frustration," as a "stress reducer," and an opportunity to "burn energy." Participation, explained one parent, allowed her child "to get his frustrations out so it doesn't all stay cooped up inside him."

Opportunities to release energy and relieve frustration in socially appropriate ways were often associated with decreases in negative behaviors, which parents noted as extremely important for their own quality of life and that of their children. For example, one father explained, “We were restraining [child’s name] every day to prevent him from doing property damage or harm to himself. When we started a program of very intensive physical activity, those things melted away. It’s really hard to explain how important the benefits are. It has truly changed our lives.”

Parents also valued recreation as an opportunity to develop social relationships with peers, as one participant noted, “recreational activities are about building relationships.” In addition to friendships, peer relationships provided their children with opportunities to “mimic and learn some of their more age-appropriate, developmentally-appropriate behaviors.”

#### **“How Much Do I Want to Fight?”**

The most prevalent theme expressed by parents was their continuous battle for access to recreation and social opportunities. One representative comment included,

“Our experiences for the most part have not been positive. We found a few select things that they have been doing, but we have not found them to be the most welcoming. We were turned down for group swim lessons. We’ve been turned down for tennis lessons. And all because of their diagnosis. Even with me saying that they are coming with help, we’ve still been turned down.”

Parents did not always wish to be the ones taking on the responsibility to pave

the way for access; and as one parent stated, “I would like for it to be less of a fight; to have to dig and scratch and claw for every single little thing that may or may not come down the pipe.”

The frustration level took its toll to the point where some family members felt hopeless. Several parents questioned how much they should fight before a toxic environment was created. As one individual questioned, “If they don’t want my kid there, how much do I want to fight? That’s the environment that I’m putting my child into. And that nasty environment is then going to trickle down to the other kids that are in there too. They are going to pick up on that. So, do I really want my child there?”

When comparing perspectives of parents based upon the ages of their children, it was clear that as children grew older, community access became increasingly difficult. Representative comments included, “it becomes more and more difficult as she has grown older.” Rather than an increased persistence of community agencies to deny access, the growing divide between the abilities and social interests of their children and their peers without disabilities made access more problematic. For example, one parent of a young adult reflected, “He participated in soccer up until about fifth grade. When they get to a certain age the typical kids get really strong and you’re afraid that they’re going to get hurt or something.”

#### **“We Run Non-Stop, 24/7, 365”**

Parents’ roles as facilitators of their children’s recreation were fatiguing. Their efforts to support their children’s participation did not end when program access was finally realized. In many cases, parents had to actively participate alongside their children. One parent poignantly described the exhaustion that results, “It is

exhausting to be a parent of two special needs children. We run non-stop, 24/7, 365 days a year. We are never given a break. So while the other parents are sitting down on the sidelines watching their kids play, we've got to be out on the field; we've got to be running up and down the field. We never get to sit down and enjoy the game." These efforts provided minimal opportunity for parents of children with disabilities to socialize or connect with others on the sidelines. Parents were angry with this "reality," as one individual described her situation, "You provide all of the assistance so that your kids can play, because they're not going to do it for you. You can pay us and we'll take your money, but you have to do everything."

Furthermore, focus group participants were concerned about the potential negative impacts that their continued presence would have on their children's experiences and peer relationships; "It may be okay at five or six for mommy to play with you, but at 10, 12, 13 years of age, it's not going to be okay for mommy to be running down the field with you. Do you know what that is going to do to their self-esteem? They're going to be outcasts at that point."

#### **"He Isn't Going to Give Your Child Autism"**

Parents provided myriad examples of their feelings of isolation and the multiple impacts that community members' negativity and stereotypical thinking had on their family's experiences. In one such example, a mother described, "When [child's name] was little, we used to go to sandboxes and pools often. Whenever we arrived, I'd see other parents pack up their kids. I had to have the discussion with them that this isn't contagious; he isn't going to give your child autism." Another stated, "Educating your family is hard enough, let alone somebody who

thinks their kid is just so spectacular and special as the top scorer. And here's your child, 'the kid who is dragging everyone down.' And then the parents start whispering things."

Anticipated reactions from community members often led to further isolation. For example, "If I have to go to an event where all the kids, or most of the kids, are typically functioning, I'm on pins and needles. Is he going to pull somebody's hair, is he going to do this, is he going to do that, is he going to have a bowel movement? It's all of these things. It's so stressful that I'd rather not go." Some parents turned to participation in segregated activities designed specifically for children with disabilities and their families. One individual noted, "I don't feel like I have to explain him or that people are impatient or staring at him. Everybody knows that everybody there has different needs and is accepting of that."

#### **"Being Accepted for Who They Are"**

Access to the community was merely their starting point as a majority of parents had dreams and desires for their children that were not currently being realized. Parents dreamt of inclusion and acceptance. One mother explained, "If they ever had any inkling that they wanted to try any sport, no matter what it was, I would want them to have the opportunity to do it in an inclusive setting. And I would want them to feel like they were accepted by the program and they weren't just the exception to the program." Another parent explained, "Just being included is probably the biggest goal. But if they could have some success, that would be really lovely." When asked to expound upon "being included," the parent replied, "Being accepted for who they are. Not just a child with autism. Not just a kid with a disability. But, whatever they

come to the table with, to be accepted.” The desire for social connections with same age peers ran deep among the participants; “She would like to be with others her age. Mom isn’t her age so it would be nice to have others her age to socialize with and to do things with.”

A few parents had fleeting experiences with their children being included and accepted, and they described these moments as if they were “magical.” A father described his son’s experience in Little League, where over the years, his peers gained an understanding of his son’s desire to not only be on the team, but a part of the action. These youngsters took steps to ensure that his child was successful as a ballplayer and a teammate. However, this father was also realistic in that he was aware that this group of peers and their families were not representative of the community, as he ended his discussion stating, “The families, the teammates, were just exceptional.”

### **“I Can’t Gamble with His Safety”**

Parents were conflicted by their simultaneous desires for their children to be part of inclusive settings and their need to keep them safe. Several parents expressed fear when their children participated with their peers without disabilities. As one parent noted, “I worry about him getting hurt, or not selected to play, or treated differently; feeling excluded.” Another parent grappled with the notion of understanding conceptually that she must let go of her transition-age son, but emotionally she felt the need to protect him from what she perceived surely awaited him when she was not there to protect him:

“A part of you is afraid, because of the social interaction skills and everything going on. It is a

safety net [referring to segregated activities with peers with disabilities] and it’s a fine line that you have to cross when you send your child ‘on over to the other side,’ as I call it, with typically developing children that might not understand him.”

Parents experienced substantial anxiety concerning the safety of their children where program leaders or staff lacked the training and understanding necessary to accommodate them. For example, one parent admitted, “being part of any type of recreational activity in [agency name] scares me, because no matter how good their intentions are, they are not trained well enough to keep my son safe. I don’t have confidence in the programs to be able to keep him safe. I can’t gamble with his safety.”

Fears related to safety appeared particularly pronounced among parents of children with autism, often related to their wandering from the program area. For example, “Don’t ever turn your back on him because he’ll be halfway into the next state. And you can tell someone [recreation staff] that, but getting them to believe that...” This parent further explained how her prior attempts to educate staff about this problem were met with a belief that she was exaggerating as an overprotective mother. These fears regarding their children’s safety were at the crux of the inclusion debate. One parent offered her opinion that, “It’s important that he has the inclusion, and I get all that... So it’s a real tough battle between how appropriate it is to send him to a typical camp for a 13-year-old, because I’m not comfortable with that. He needs somebody with him.”



### **“If They Want Our Business, They Need to be Accommodating”**

Parents knew exactly what they wanted policymakers and recreation providers to know about their plight. They desired to send a clear message to these professionals concerning the unacceptability of the current lack of access and accommodation. First, they wanted decision-makers and practitioners to understand the long-term implications of continuing to deny their children access, stating “We’re setting these kids up to fail because they’re not part of anything... If we don’t do something it’s going to be a burden on society later on.” Second, they wanted these individuals to know that they were a growing contingency that would need to be reckoned with, as one parent proclaimed, “Let policymakers know that we are a growing population; it’s growing and it’s going to continue to grow.” They believed that efforts needed to commence by increasing the awareness of policymakers about the expanding nature of the issue. “We need to raise awareness somehow. A community leader made a comment to me that funding for people with special needs will not be available because the issue is not widespread, and it does not affect as many people as other community needs. They have no idea! It affects parents, siblings, and the extended family.”

Additionally, parents wanted recreation providers to understand that the growing size of their constituency made excluding this demographic simply a poor business decision. These families always network with each other; consequently, information concerning what is successful, and conversely, what does not work, spreads quickly among families, friends, coworkers, and other community members. As one parent warned,

“I hope they realize that they are turning away a lot of people with that kind of attitude. And we know people; we talk. It’s not like the number of kids with autism is going down. And all it takes is one bad experience, and everybody we know, knows about it. And there goes your program. So if they want our business, they need to be accommodating.”

Finally, parents made it perfectly clear that agencies must be more proactive in serving their children, especially after years of disservice.

“They’re going to have to reach out to us at this point, because they have such a bad reputation. I can’t imagine trying to enroll my kids in anything that [agency name] has. It’s really disgusting how they’ve treated our kids. So, at this point, I’m saying, you come to us.”

### **Discussion**

A series of parent focus groups provided a wealth of information regarding perspectives on community access. Themes that arose made it clear that parents valued recreation participation as an important aspect of their children’s quality of life, but found access to community programs severely limited. Respondents were fatigued by the overwhelming responsibility they were asked to undertake in support of their children’s participation when access was finally gained, and were experiencing a great deal of isolation in doing so. Additionally, parents had dreams and desires for their children’s full inclusion, but struggled with internal conflict between active engagement and

social participation and the need to keep their children safe.

It was interesting to note that despite their vivid desires for full inclusion, parents also encouraged and supported segregated or specialized programming out of concerns for safety and emotional well-being. Thompson and Emira (2011) noted this paradox among parents of children with autism, concluding "...how one squares the circle between the principle of full inclusion and meeting the practical needs of families is uncertain" (p. 75). This dilemma between advocating for inclusive versus segregated programs within the context of safety will continue to grow until program staff become more willing and better equipped to serve individuals of varying abilities.

It is evident that community recreation providers have a substantial amount of work before them if they are to gain the trust of this growing constituent base. From our focus group research, it became clear that entire families were impacted by this lack of access, greatly broadening the scope of this issue. Family members are isolated, fatigued, and frustrated, and consequently experiencing diminished quality of life. Consistent with the findings of Blue-Banning and her colleagues (2004), parents remain stressed and exhausted due to the perceived necessity to continue to fight for services, cope with poor provider attitudes, and deal with continuous breakdowns in their relationships with practitioners.

### **Inclusive Community Services: Everyone's Responsibility**

Community is noted to be a core value of parents and advocacy agencies such as The Arc and Autism Society, as it is believed that individuals with ID/DD have fundamental moral, civil, and constitutional rights to be fully included and ac-

tively participate in all aspects of society. Most would agree that the opportunity to participate in the community through recreational activities is a highly valued part of our society. The focus group parents recognized this and acknowledged that the rights of their children to be included are largely being ignored.

An important role for agencies working with individuals with disabilities is that of advocate, which includes guidance in the direction of self-advocacy. Traditionally, advocacy organizations have intervened on behalf of individuals seeking access to community programs. From the standpoint of sustainability, it is vital that individuals and their families learn and continue to develop the necessary skills to advocate for themselves and their children. Additionally, as indicated in the focus group discussions, parents are in the best position to describe the support needs, abilities, and interests of their children. It was also pointed out in these discussions that families control the purse strings and are the taxpayers who support many of the agencies and organizations that exclude their children. Although parents are armed with a great understanding of their children and are willing to pay for recreation services, not every parent has the skills necessary to effectively communicate their child's needs to recreation providers. An important role for advocacy agencies is to build a bridge between families and the recreation agencies who will be serving their children.

Training and supporting parents and practitioners to collaborate regularly with each other can make the difference in the participation options for an individual. Without sharing this knowledge, both parents and recreation providers will be frustrated with their disjointed efforts. As a partner with families, advocacy

agencies may be in the best position to empower groups of parents, in addition to individual families, thereby establishing a base of natural supports among the participating families. The need for support among families encountering similar obstacles was cited in our focus group discussions as a reason to seek segregated programs.

The frustration cited by parents in the focus groups regarding the lack of access to recreation services, and the battles that ensued, led to a surrender of sorts as parents gave up the battle from sheer exhaustion. Advocacy agencies could do more to support families than merely provide additional tools for the parents' utilization. A proactive approach to help change the attitudes and responses of recreation service providers could be pursued by advocacy agencies. To facilitate family-professional partnerships, advocacy agencies could utilize the outcomes emanating from Blue-Banning et al's. (2004) research that emphasized the following themes for effective partnerships: respectful communication, shared commitment, equity in decision-making, perceive that others on the team demonstrate competence, trust of others, and regard for each other with esteem through actions and communications.

Moreover, Mactavish and Schleien (1998) in their survey and interview research with families that included children with a developmental disability, identified four formal methods that perhaps could be implemented by recreation providers in support of families including (1) hiring staff who are committed to including families and self-advocates in program planning and service delivery, (2) developing a needs assessment to generate ideas about programs and services that reflect family needs and interests, (3) creating an advisory board that included

parents as active members, and (4) hosting focus groups to explore and evaluate new initiatives and existing programs.

Parents participating in our focus groups desired both segregated and inclusive options, based on several factors. For some, the perceived safety in a segregated environment was the driving force. For others, the desire to participate with families in a similar situation led them to choose a segregated program. For many, the lack of available inclusive opportunities left no option other than a segregated program. Families and advocates will not accept the limitations imposed by recreation service providers that exclusively offer segregated programs or programs that are limited to accommodations only in one facility within a geographic area. Service providers often refer families to special needs program options, so as to provide a service without having to provide accommodations within an inclusive setting. This perpetuates the notion that inclusive recreational opportunities are only for the support of those with disabilities, while in reality all people benefit from a focus on individualized needs and accommodation. While there is a perceived benefit of segregated programs for certain individuals, it should be a choice. Separate, segregated recreation programs should not be an excuse or default program based on one's label or tradition.

## Conclusion

As stated, parents of children with ID/DD are most familiar with their children's strengths and challenges. Advocacy agencies may have an important role to play in facilitating the communication of parents' knowledge and wishes with community recreation agencies, so that a partnership is formed and all participants benefit. Parents should not be shy about

getting or remaining involved, realizing that the continued pressure generated by informed parents and advocates not only gives the system a “push” in an essential way, but supports officials of the system in fulfilling their mission as recreation service providers to the entire community. There is a responsibility of all community organizations working with children to determine the best way to serve each and every child, regardless of ability level. While parents should be encouraged to partner with service providers to help identify supports needed for optimal participation, it is ultimately the responsibility of the recreation provider to develop accepting attitudes, competencies, and efficacy-based practices to include all children in programs for the benefit of the entire community.

What is the potential impact of such collaborative efforts on our future? By supporting inclusive opportunities, recreation providers and advocacy agencies are in a position to help families look beyond the struggles of today and envision

their children as adults who are part of the greater community. Social inclusion is for the betterment of the community at large, as all seek to live socially connected, fulfilling, and productive lives as adults. The teammate on the soccer field and fellow actor in the theatre program could very well become the supervisors and directors who decide to hire young adults with disabilities 15 to 20 years into the future, based on their exposure, as children, to fellow participants with disabilities. Recreation agencies are responsible for arranging their environments and preparing their staff to provide increased access and facilitate social inclusion in their programs and activities. These efforts will make an impact on all individuals’ participation, with and without disabilities. When everyone is actively and positively involved—from recreation agency administrators and practitioners, to parents, advocates, and consumers—we all reap the benefits. Only then can equity be attained and community belonging and social inclusion truly be achieved.

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