

Collaborating to Support Meaningful Participation in Recreational Activities of Children With Autism Spectrum Disorder

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Participation in recreational activities is associated with increased quality of life and life satisfaction; it is essential to our lives. Individuals with autism spectrum disorder (ASD) experience restriction in the range of recreational activities in which they participate. Complex factors impede participation in recreation activities of children with ASD, underscoring the need for professionals to work with parents to enhance participation in recreational activities. Given opportunity and adaptations, individuals with ASD can participate and enjoy the same recreation activities as others. This article describes the application of family-centered care and collaborative teaming principles to maximize the participation of children with ASD in recreational activities. **Key words:** *autism spectrum disorders, children, collaborative teaming, participation, recreation*

ALTHOUGH participation in recreational activities is important (Coyne & Fullerton, 2004; Mactavish & Schleien, 2004), for many individuals with disabilities, such participation is restricted by impairments associ-

ated with the disability (King et al., 2003). As an example, children with autism spectrum disorder (ASD) are likely to have limited recreational opportunities considering their social, communication, and behavioral impairments. Yet, planning for participation in recreational activities is seldom a focus in their educational programs. Furthermore, considering the multifaceted factors restricting participation of children with ASD, it is unlikely that parents, teachers, or therapists alone would be able to promote participation in a range of meaningful activities. Consequently, parents and professionals must collaborate in defining, planning, and implementing participation in recreational activities.

This article describes the importance of participation in recreational activities and highlights the known and potential impact of ASD on children's recreational participation. Additionally, it offers an application of collaborative teaming and family-centered care

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principles to support the recreational participation of children with ASD.

PARTICIPATION AND THE IMPORTANCE OF RECREATION

Participation represents “the complete range of domains denoting aspects of functioning from both an individual and a societal perspective” (World Health Organization [WHO], 2002, p. 8). Recreation, a participation domain, includes involvement in formal and informal activities such as play, sports, relaxation, going to the theatre, crafts, playing music and tourism (WHO, 2001). Recreational participation is also recognized as a fundamental right in the United Nations’ Convention on the Rights of the Child (1989), included as a complement to academic programs in the No Child Left Behind Act of 2001, included as a related service in the Individual with Disability Education Improvement Act of 2004, and mandated nationwide to be accessible to all individuals through the Rehabilitation Act of 1992.

Unfortunately, children with disabilities participate in fewer recreational activities than typically developing peers, with negative impact on long-term child outcomes (Faison-Hodge & Porretta, 2004; Mancini, Coster, Trombly, Timothy, & Heeren, 2000). This is problematic because recreational participation has extensive benefits for children with disabilities. It can reduce behavioral and emotional disorders, help develop social relationships and friendship, improve physical and mental health, and help children develop their interests (King et al., 2003; Mactavish & Schleien, 2004; Rae-Grant, Thomas, Offord, & Boyle, 1989; Wilson, Arnold, Rowland, & Burnham, 1997). Recreational participation is also associated with improvements in family relationships and family life satisfaction (Mactavish & Schleien, 2004). Moreover, participation in recreational activities is related to an increased quality of life and life satisfaction, both determinants of health and well-being (Law et al., 2004).

RECREATIONAL PARTICIPATION OF INDIVIDUALS WITH ASD

Autism spectrum disorder is characterized by core deficits in social skills, communication, and restricted, repetitive, and stereotyped patterns of behavior (American Psychiatric Association, 2000). The communication and social impairments associated with ASD have been studied extensively, and a thorough review of this literature is beyond the scope of this article. Briefly, children with ASD have difficulties with pragmatic and paralinguistic language, social cognition, and executive function (Harris et al., 2006; Landa & Goldberg, 2005). Individuals with ASD may also have sensorimotor differences, such as motor initiation and planning difficulties and fine motor delays (Provost, Lopez, & Heimerl, 2007; Rinehart et al., 2006). Each of these impairments has the potential to affect participation in recreational activities.

Autism spectrum disorder also has important psychosocial impacts on affected children and their families that can influence their ability to participate fully in recreational activities. For example, children with high-functioning autism (HFA) have a higher prevalence of anxiety and depression than typically developing peers (Belini, 2004; Gillott, Furniss, & Walter, 2001; Kim, Szatmari, Bryson, Streiner, & Wilson, 2000). They also report feelings of loneliness to a greater degree than reported by their peers (Bauminger, Shulman, & Agam, 2003). Similarly, mothers of children with HFA report poor physical and mental health (Allik, Larsson, & Smedje, 2006) and siblings of children with ASD report poor quality of life (Verté, Roeyers, & Buysse, 2003). Notably, the literature suggests that such psychosocial impact can be reduced when children with disabilities, such as those with ASD, and their families participate in recreational activities (Mactavish & Schleien, 2004).

Orsmond, Krauss, and Seltzer (2004) found that walking or “getting exercise” was the most frequent recreational activity mothers ($n = 235$) reported for their adolescent or

adult children with ASD. They also noted that approximately half of the individuals with ASD engaged in a hobby and between one-third and two-thirds participated in at least one recreational activity weekly (Orsmond et al., 2004). In a population-based study of parents of children with special needs, Wagner et al. (2002) found decreased participation in recreational activities of children with ASD as compared with peers with other disabilities. For example, approximately 30% of the children with ASD never visited friends, 65% never received phone calls, and 12% had no out-of-school interactions with friends. (Wagner et al., 2002). These participation restrictions were also seen in an observational study of 18 children with HFA who spent only about half of their time in social interaction with peers during unstructured time when compared with typically developing children (Bauminger et al., 2003). This social isolation appears to worsen with age because half of the adolescents and adults with ASD are reported to have no peer relationships (Orsmond et al., 2004).

In the context of the known and potential benefits of recreational participation for individuals with disabilities, concerns are raised by this emerging body of literature indicating that individuals with ASD have restrictions in recreational participation points to the need to include recreation. It also is a critical program component for educational and rehabilitative programs for children with ASD.

ENHANCING RECREATIONAL PARTICIPATION OF CHILDREN WITH ASD

To successfully promote recreational participation, it is essential to understand the factors influencing this participation. Participation restriction in individuals with disabilities is not based solely on their diagnosis and impairments; it is a complex and multi-determined phenomenon that includes environmental and personal factors (Fougeyrollas et al., 1998; King et al., 2003; Law et al., 2004). King et al. (2003) developed a comprehen-

sive, strength-based, socioecological model that categorizes the factors mediating the participation of children with disabilities (i.e., child, family, and environmental factors). The factors identified so far as affecting participation in recreational activities of individuals with ASD are illustrated in Figure 1. The interplay is noted among the child's impairments, the family's style, preferences, and demands, as well as environmental or community-based limitations in restricting a given child's ability to participate in an array of recreational activities. All of these factors need to be considered when an interdisciplinary team explores the possibilities for enhancing a child's participation in recreational activities.

To enhance participation in recreational activities of children with ASD, we propose that principles of collaborative teaming and family-centered care be employed. Ultimately, the team should develop an intervention approach that embraces the strengths and interests of children with ASD, takes into account evidence-based intervention strategies, and builds on the strength of interdisciplinary service provision. Although these principles are not new, their application offers a useful framework for facilitating meaningful participation in recreational activities of children with ASD.

In simplest terms, *collaborative teaming* can be defined as two or more people working cooperatively to achieve a common purpose (Rainforth & York-Barr, 1997). It is a voluntary relationship that requires equality among team members, depends on shared responsibility for decision making, and works to achieve a common goal. Collaborative teams evolve through five components: building team structure, learning teamwork skills, problem solving and action planning, coordinating team action, and resolving conflicts (Snell & Janney, 2005). Collaborative teams change and mature over time as team members change, goals are achieved or adjusted, and additional challenges present themselves. Family-centered care is an effective educational and healthcare service delivery

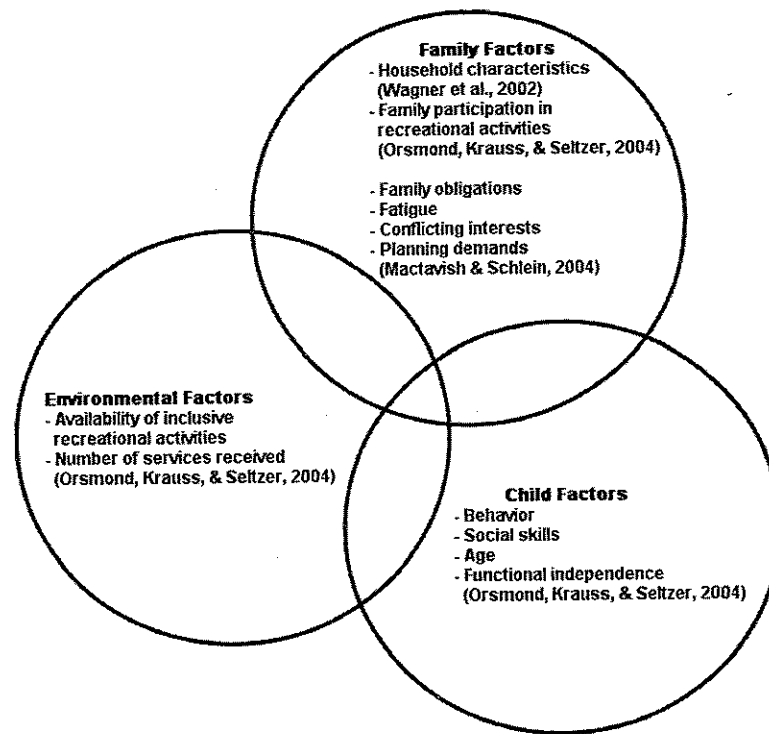


Figure 1. Factors known to affect participation of children with autism spectrum disorder identified empirically.

approach that emphasizes partnership among service providers, children, and their families through respect, communication, and collaborative participation in all aspects of service delivery, from goal setting to implementation (Freitas & Shelton, 2005; Prelock, Beatson, Bitner, Broder, & Ducker, 2003). Collaborative teaming is a natural fit for services based in family-centered care because it espouses similar and complementary principles.

Therefore, a family-centered collaborative teaming approach is proposed to expand the recreational participation of children with ASD. This approach requires a series of interrelated, although not necessarily sequential, steps as illustrated in Figure 2. The team follows the parents' lead to determine a child's priority outcomes and decide whether or not recreation falls within these priorities. The team, including the parents and the child, then formulates the purpose or the goal for enhancing recreational participation

of this child. To do this, and to later develop the action plan, the team may need to gather additional information about the child, family, and environmental factors that impact the child's recreational participation. The action plan generated from the goal will likely have several steps. These include identifying accommodations, developing instructional plans, and/or providing direct interventions. Team members take responsibility for implementing specific parts of the plan and establish a timeline and method of communication among team members. Finally, the team agrees on a method to determine when an action step is successful and when it needs to be modified.

Two hypothetical case examples follow that demonstrate the application of collaborative teaming and family-centered care principles to ensure meaningful participation of children with ASD, specifically a child with ASD and limited verbal skills and a more verbal child

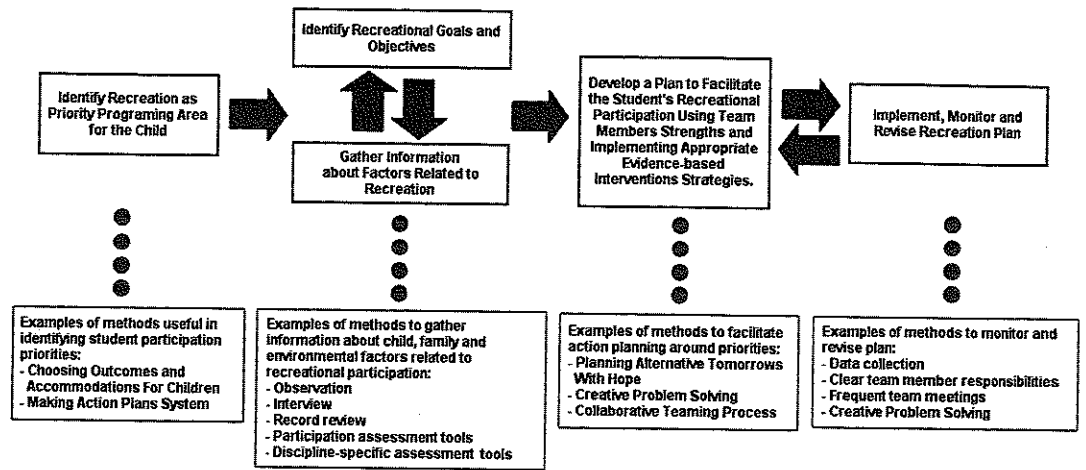


Figure 2. Applying the principles of collaborative teaming and family-centered care to recreational participation.

with ASD. Each example also identifies the child, family, and environmental factors that impact participation.

FACILITATING PARTICIPATION OF A CHILD WITH LIMITED VERBAL COMMUNICATION

In the first hypothetical example, a school team collaborates with a family to facilitate participation in recreational activities of a 7-year-old girl (hereafter referred to as Jane) with ASD and limited verbal communication. Several factors influence the success of this collaboration in fostering recreational participation. Child factors include limited to no verbal skills (i.e., child points and uses pictures), expression of frustration through tantrums and self-injurious behaviors, and limited functional independence. Family factors include one younger sibling and an elderly grandparent living in the home, both parents working outside the home full-time, and family recreational preferences for sedentary activities (e.g., watching television and reading) except for a weekly family swim time at the local public pool. Environmental factors affecting participation include Jane's attending a school committed to the integration of all students

with disabilities into regular education classrooms. The Individual Education Plan (IEP) team, which includes Jane's parents, uses a family-centered, collaborative planning tool, *Choosing Outcomes and Accommodations for Children* (COACH; Giangreco, Cloninger, & Iverson, 1998), to develop the child's IEP.

COACH is a research-based, standardized process designed to identify outcomes for a child's educational program (Giangreco et al. 1998). Families are asked to consider and identify areas of development, learning, and life activities (i.e., communication, socialization, personal management, leisure/recreation, selected academics, home, school, community, and vocational) they wish to be priority outcomes (Giangreco et al.). The COACH process is a strengths-based approach to intervention planning. It aligns with special education law and promotes collaboration on the part of professionals involved with children with intensive special education needs.

Through the COACH family interview (Giangreco et al., 1998), enhancing meaningful participation in recreational activities is identified as a priority. Because the child's current independent activities are limited to watching videos and bouncing on a ball, the parents identify increasing her range of activities as a priority outcome. Therefore, an IEP

goal could be written about recreational participation or the team might decide that additional information should be gathered before writing recreational goals. In this situation, the team decides to gather additional information first. The occupational therapist (OT) completes an assessment of Jane's interests, using the Hobbies and Sports cards of the *Pediatric Activity Card Sorting* (PACS; Mandich, Polatajko, Miller, & Baum, 2004) and a parent interview.

Various methods can be used to ascertain children's interests related to recreational activity ranging from interviews of parents, siblings, and classmates to observation during free play and the administration of standardized tools such as the PACS. The PACS is a self-report assessment composed of picture cards, each representing an activity, that children sort into piles. Children rate both what they currently participate in and what they would like to do. Two other measurement tools assess the domain of participation from the child's point of view: *Children's Assessment of Participation and Enjoyment* (CAPE; King et al., 2004) and the *Activities Scale for Kids* (Young, Williams, Yoshida, & Wright, 2000); whereas others measure participation through parent, therapist, and teacher ratings, such as *the School Functional Assessment* (Coster, Deeney, Haltiwanger, & Haley, 1998).

Monthly team meetings are used to review the information regarding Jane's recreational interests, amend the IEP to include a recreational goal, as well as develop and monitor an instructional plan to achieve this goal. Results of the PACS and an interview with a parent in this case reveal Jane's preference for activities in which she can move. The teacher identifies an after-school gymnastics class Jane can attend in which she can have opportunities to interact with her peers. The team then uses the information gathered to write an IEP goal related to recreation: *Given needed support, Jane will participate actively in 30 min of a weekly after-school gymnastic program with 80% attendance.* The team also develops objectives to enable Jane to meet her recreational goal. For example: (1) Jane will transi-

tion to gymnastics class with ease (i.e., without screaming or self-injurious behaviors) 70% of time given the use of a social story to prepare her for the class and a visual schedule indicating gymnastics was the next activity. (2) Jane will wait for her turn to use each apparatus 80% of the time with a visual prompt and/or physical cueing from her paraeducator. (3) Jane will respond to an initiation by at least one of her peers weekly using her communication board.

In keeping with the principles of Individual with Disability Education Improvement Act of 2004, and special education best practice, goals and objectives should be student-specific and discipline-free, provide a context for goal implementation, and be readily measurable by any observer. Goals and objectives should measure what the student is gaining, as opposed to, for example, adult implementation of supports. Objectives should be subcomponents of learning leading to goal achievement. As illustrated in Jane's situation, recreational participation can be included as an IEP goal, although for other students, it may be more appropriate to include recreation as a related service or general support to achieve, for example, communication or social goals. Recreational participation goals can be activity specific as presented in this example or more exploratory in nature (e.g., the child will try three new recreational activities) depending on the identified individual child, family, and environmental factors.

Using the information collected, team members then brainstorm supports and develop an action plan to ensure the success of the student in a given recreational activity. Responsibilities are assigned to each team member to maximize Jane's success in a gymnastics class. The physical therapist and the physical education teacher introduce the gymnastics' equipment to Jane to prepare her for learning new motor tasks, following the routine of the gymnastics' class and interacting with peers. The speech-language pathologist (SLP) writes a social story describing the basic rules and expectations for the class and creates a communication board for use in this new environment. The SLP also reviews previously

taught peer mediation techniques with the team and provides applications in gymnastics class. The special educator writes an instructional plan for the paraeducator to implement. Both the special educator and the SLP monitor the activity through observation during gymnastic class, brief conversation with the paraeducator and Jane's parents, and review of data collected for each objective. They respond to the mandate by the IEP team to adjust the plan in the first month, seeking input from other team members as needed prior to the next team meeting to review any needed changes. Some evidence-based intervention strategies (e.g., social story, peer mediation) found to be useful with children with ASD are mentioned to demonstrate how they can be used to support recreational participation. A description of these strategies can be found in Prelock (2006).

This first hypothetical case example describes the actions of a mature, family-centered, collaborative team that functions in a supportive environment where team members are able to meet on a regular basis, fostering their collaboration. Team members share roles and responsibility for implementing and modifying action plans. Families' realities and preferences are respected. Parents and children (as appropriate) are involved in each step of the decision-making and implementation processes.

FACILITATING PARTICIPATION OF AN ADOLESCENT WITH HEA

The second hypothetical example describes a school team that collaborates with a family to facilitate participation in recreational activities of a 15-year-old adolescent boy (hereafter referred to as Tom) with HEA. As part of the transition from middle to high school, Tom and his parents meet with both school teams to review Tom's IEP and discuss his successes, strengths, and support needs as he moves to high school. During these meetings, the need to strengthen the secondary transition component of Tom's IEP, namely, preparation to the transition to adulthood, arises. Assuming that Tom's IEP

team, which includes himself, his mother, and a select group of school team members, recognizes the importance of this transition, they might choose to engage in a *Making Action Plans System (MAPS)* process (Forest & Pearpoint, 1992) with Tom and his mother.

Making Action Plans System is a collaborative process that brings a team of key people in a student's life together to collect information and create an action plan around the vision that families have for their children and that children have for themselves (Forest & Pearpoint, 1992). A MAPS plan is created through a facilitated discussion, using probing questions focusing a team on the hopes and dreams of a child, what team members want to avoid or fear, the strengths and talents the child exhibits, and barriers to achieving the articulated dream. Children, to the extent possible, are an integral part of their MAPS process.

Through the MAPS process, Tom might indicate dreams of attending college, living on his own, developing close friendships, getting married, and participating in more leisure activities outside his home. The IEP team proceeds by identifying priorities for Tom's upcoming school year as well as future years in high school. These may include priorities such as developing leisure activities that build on his strengths, fostering friendships, and planning for a college education, all areas of participation.

Through the MAPS process, factors potentially influencing recreational participation may arise. Such factors may also be documented in the "Present Level of Performance" section of the IEP. For students like Tom, child-based factors might include fluent expressive communication with difficulties with non-literal language and social cognition; greater ease of interaction with adults as compared with same-aged peers; anxiety controlled through medication; sensitivity to sounds; restricted interests to computer games, television game shows, books, action movies, and mathematics; and, grade-level performance in mathematics, history, and computer science. Family factors include a single-working parent, limited financial resources, and limited natural supports. Environmental factors

include attendance in a new school, living in a rural setting, educational support provided by a paraeducator for part of the day, and daily access to a quiet independent work area.

This newly forming team struggles at first to collaborate in developing a cohesive plan to achieve Tom's priorities from the loosely formed plan that arises from the MAPS process. The team chooses to follow-up on the MAPS with its extension, the *Planning Alternative Tomorrows with Hope* (PATH) process, through which they collaboratively refine the action plan (Jonikas, Cook, Fudge, Hlebechuk, & Fricks, n.d.). The PATH process allows the team to develop achievable long- and short-term goals, provides clear timelines for achieving goals, and assigns team members to accomplish the steps toward a goal (Falvey, Forest, Pearpoint, & Rosenberg, 1994).

Through the PATH process, the team determines that no additional IEP goals around recreation are required for Tom's IEP because recreational activities may be part of a milieu where his communication and social goals are addressed. The first step of the action plan requires the school guidance counselor and the OT to gather additional information about Tom's recreational interest and availability of recreational activities in the community. The OT asks Tom to complete general interest checklists and the CAPE (King et al., 2004).

The CAPE is a self-report tool used to document how children participate in everyday activities outside those mandated for school and identify their activity preferences (King et al., 2004). Children rate 55 activities on 5 characteristics, such as frequency and location of participation in an activity, degree of enjoyment of the activities, and interest in activities in which they may or may not have participated. The 55 activities are then grouped into five categories: recreational activities, physical activities, social activities, skill-based activities, and self-improvement activities.

The IEP team then meets to review the information gathered. Through the CAPE, Tom has identified, in addition to his usual recre-

ational interests, a desire to participate in school clubs, hangout with friends, and have a pet. Recognizing the family and environmental factors that impede recreational participation in the broader community, the team decides that an after-school program is the most appropriate first step. A team member, Tom's math teacher, proposes the school math club as a recreational activity that builds on Tom's strengths and interests. Tom, who is present during the meeting, agrees that it is a good idea before the team continues planning. A conversation follows about challenges that Tom may experience while participating in this club. The team discusses the need to provide support to facilitate positive social interactions during math club meetings and competitions, for Tom to learn the mechanics of the competition, and to manage Tom's dislike of noises and busy places.

A plan is generated to enable Tom's participation. The SLP helps Tom understand the social interactions in the math club and teaches him appropriate responses through video modeling. Tom asks the math club advisor to teach him the mechanics of answering questions and the competition format with support from his special educator. The OT discusses self-management strategies (e.g., guided relaxation, wearing earplugs) with Tom to address his anxiety and sound sensitivities during the competition. The special educator charts the frequency with which the strategies are implemented during a few practices and games. After the first competition, modifications to the strategies are recommended such as the need for a teammate to touch Tom's arm gently when he needs to be reminded to focus on the game. The IEP team meets bimonthly to discuss progress and modify the plan as needed. During this meeting, the school guidance counselor offers to meet a few times with Tom to explore further community recreation.

With older children, the inclusion of the student in the family-centered collaborative teaming process is essential to a successful outcome. Newly forming teams may have challenges with working collaboratively

and need to rely more heavily on specific processes such as PATH to develop and implement a plan to enhance recreational participation.

CONCLUSION

In summary, participation in recreational activities has the potential to support the development of function in the area of typical impairments in HFA (i.e., communication, so-

cial and executive functions), to lessen the impact of the symptoms of autism on the child and the family, and to promote quality of life and well-being. To enhance recreational participation of children with ASD, families and professionals must work collaboratively to determine the child's interests, identify barriers to recreation, and develop a system of supports that allows the child to participate in a wide range of meaningful recreational activities.

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