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Creating Participation Opportunities at a Camp for Children With Autism and Asperger Syndrome

■ Judith Banet, Josie Gilbert, Monika Gmytrasiewicz, Mario Pereyra, Kendra Reynolds, and Kathleen "Mo" Taylor, OTR/L

Autism is a neurobiological disorder characterized by impairments in a person's ability to communicate and relate to others and by its affect on behavior (Autism Speaks, 2008). Social impairments may lead to strained relationships with friends and family members. Autism often is associated with rigid routines and repetitive behaviors, such as obsessively arranging objects or following very specific routines (Autism Speaks, 2008). Symptoms can range from mild to severe, and persons with autism display a unique combination of different features. Today, an estimated 1 in 150 children are given a diagnosis of autism, making it the third most common childhood disorder behind mental retardation and language impairment (Autism Speaks, 2008). Autism affects children of all racial, ethnic, and social groups and is four times more likely to affect boys than girls (Autism Speaks, 2008).

Asperger syndrome is a neurobiological disorder on the autism spectrum, sharing similar characteristics with autism; however, persons with Asperger syndrome have a typical IQ and have developmentally appropriate language acquisition (Griffin, Griffin, Fitch, Albera, & Gingras, 2006). Children with Asperger syndrome face the same social issues and behavioral challenges as others with autism. Going to summer camp provides an ideal setting for these children to engage in group social interaction where they can practice positive communication and behaviors.

Camp Rising Sun

Laura White, a New Mexican physical therapist and mother of a child with autism, worked with a core team of professionals to create a local summer camp for children with autism and Asperger syndrome. In 2006, Camp Rising Sun (CRS) took flight to provide a specialized summer camp experience for children with autism, offer respite for their parents and caregivers, and provide opportunities for university students and professionals to gain experience working with this population (CRS, 2008).

Eighteen children from 8 to 13 years of age participated in the first 5-day camp session in 2006. By 2008, CRS hosted 59 children,

including several with typical development who served as peer models for behavior and communication skills, in two 5-day sessions. The staff consists of volunteers from the community (teachers, therapists, case workers, college students) and graduate students from different disciplines. In 2008, 12 adolescents, including 4 with Asperger syndrome, trained to be counselors. The camper-to-counselor ratio generally is one to one and occasionally one camper to two counselors. CRS is located on the grounds of Camp Oro Quay in the mountains east of Albuquerque, NM. The property is covered with evergreen trees, hiking trails, and grassy fields and has a variety of wildlife. (One night a bear was seen exploring the camp!) The camp grounds has its own swimming pool, campfire pit, bunk houses, dining hall, health center, performing arts center, and a collection of farm animals.

CRS includes activities such as horseback riding, hay rides, a ropes course, swimming, arts and crafts, music, and other leisure activities that promote motor, process, and communication skills (see Figure 1). Individualized programs are developed for campers based on their abilities, needs, and desires in order to promote their participation and engagement in camp activities. For example, one music session involved exploring movement and rhythm through dance and use of recycled percussion instruments. Participation for some campers involves dancing in a circle with the group, whereas for others observing campers during this activity is considered meeting a goal. The ropes course is another activity graded for varying abilities of the campers. While some campers climb to the top of a 30-foot wall, others put on a helmet and harness and are happy to simply cheer the climbers from below. Cheering is a form of communication considered an important component of the camp environment because it promotes social participation and camaraderie. Additionally, the ropes course provides campers with an opportunity for critical thinking, such as motor planning and problem solving, and peer interaction. Ultimately, all activities are designed to be appropriate to each camper's skill level and to build confidence and self-esteem.

Role of Occupational Therapy

A recent addition to CRS is the incorporation of occupational therapy graduate students from the University of New Mexico (UNM) as



Figure 1. Campers enjoy a self-selected activity at Camp Rising Sun.



Figure 2. Five occupational therapy students (pictured with their supervisor, Kathleen "Mo" Taylor) have a learning experience at Camp Rising Sun, a summer camp program for children with autism and Asperger syndrome. From left are Taylor, Josie Gilbert, Kendra Reynolds, Mario Pereyra, Judith Banet, and Monika Gmytrasiewicz.

camp counselors (see Figure 2). Terry K. Crowe, PhD, OTR/L, FAOTA, professor and founder of the UNM Occupational Therapy Graduate Program, along with Kathleen "Mo" Taylor, OTR/L, senior program therapist at the UNM Center for Development and Disability, created this learning opportunity as a three-credit graded

independent-study course. Ms. Taylor has 18 years of experience working with children with autism in a variety of settings, including schools, community programs, pool therapy programs, homes, and camp. The graduate students attend two full-day camp staff trainings about autism and Asperger syndrome and the camp activities and strategies that support children to excel in the summer camp environment. Additionally, in an effort to establish a client-centered approach for each camper, the students review information about each camper provided by parents and teachers, including activities of daily living, leisure activities, communication abilities, behaviors, and emotional and sensory responses.

Ms. Taylor conducts an additional half-day workshop for the occupational therapy students on visual supports, which are an integral component of the intervention strategies that the students would provide to the campers. Visual supports present abstract concepts in a concrete and manageable form that often is tailored for children with autism (Stokes, 2005), and these help to prepare campers by breaking activities and tasks into smaller components or parts. They are used to address the child's difficulty with memory and time organization, assist with language comprehension, lessen anxiety that accompanies transition from one activity to another, and facilitate independence in transitioning. Establishing a clear beginning and end for an activity is essential for understanding the completion of activities. Examples of visual supports used at CRS are visual schedules, choice boards, emotion scales, first-then boards, and communication boards.

The occupational therapy students are carefully paired with campers who would benefit from specialized supports, and each student creates a unique visual support for his or her camper. Throughout the week of camp, Ms. Taylor provides daily support to the students on the use of these visual supports, behavior management strategies, and methods to facilitate social engagement and independence in daily living skills.

Camp was a beneficial learning environment for the occupational therapy students because they worked with the campers across the contexts of the entire day, observing where challenges arose and how to modify or adapt situations to promote social engagement and independence. Spending 24 hours a day with the campers gave the students insight into the daily routines and roles of parents and caregivers, including long days, sleepless nights, self-care maintenance, and behavioral challenges. The students also experienced celebrating the campers' accomplishments, observing campers interacting positively with one another, and receiving expressions of friendship and love from the campers. They were able to gain a greater appreciation for adapting activities of daily living, implementing techniques used to increase participation, and understanding that the "spectrum" is just that: an all-encompassing range. CRS provides an exceptional learning experience in that it is as challenging as it was rewarding. This hands-on experience will make the students more competent occupational therapists in the future, and the knowledge they gained will assist them in their final year of academic study at UNM.

A Camper's Story

John (pseudonym) is a 13-year-old boy who lives with his parents and older brother in rural New Mexico. He is a third-year camper with autism and mental retardation, and a polite, helpful, and loving person. John was paired with an occupational therapy graduate student, Mario Pereyra, during camp. He came to camp with goals to increase social contact with peers, experience new activities, and explore new roles and routines in an unfamiliar context, as identified by his parents.

Based on John's individual needs, Mario created a visual schedule that included a first-then board, which is a basic visual system

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Figure 3. Games at Camp Rising Sun foster social interaction.

demonstrating one event followed by what is coming up next, with a pouch to place symbols of finished activities. This visual system facilitated social engagement and preparation for upcoming events and allowed for effective communication between John and Mario. In addition, Mario used modified communication techniques that included short statements as opposed to questions, exaggerated facial expressions, and tactile cues. Through these methods, John was able to participate in a wide array of camp activities, including climbing the high ropes course; riding horses; and participating in parallel play, such as building with connecting blocks during various self-selection activities.

John was fixated on playing with rubber ducks in a fountain. In previous years at camp, advisors reported that he was not interested in participating in any activities other than those at the fountain. The use of the visual schedule proved to be both practical and essential to successfully redirecting John away from the fountain to participate in several scheduled camp activities, accomplish many of his goals, and have a more meaningful camp experience.

John had many additional successes at camp, one of which included involvement in the typical mealtime routines at CRS. At the start of camp, John had limited patience to sit through an entire meal, typically shoveling his whole plate of food into his mouth within a few minutes and promptly exiting the dining hall without regard to others. To encourage more appropriate mealtime behavior, food items were served only after previous portions had been completed. Positive reinforcement was provided throughout the meal, encouraging a steady pace that fostered development of social skills. By the end of camp, John was able to sit through an entire meal and even eat dessert with his peers.

Conclusion

Since its inception, CRS has given children with autism and Asperger syndrome a unique, exciting camp experience found nowhere else in New Mexico. CRS provides a safe environment for campers to explore new activities; foster social interactions; increase independence; and, most importantly, have fun (see Figure 3). Camp also provides parents with the opportunity to rest, relax, and recharge while their children are away from home. With its inclusion of the UNM occupational therapy graduate students, CRS provides an exceptional opportunity for hands-on learning and professional development in a real-life context. The multidisciplinary

team of professionals and volunteers contributes to the success of this camp by designing a structured camp curriculum tailored to meet the individual needs of children with autism and Asperger syndrome. CRS is continuing to grow to meet the increasing needs of the surrounding communities, providing children with Asperger syndrome with not only a typical camp experience, but also skills that will benefit them throughout their lives. Camp also allows future professionals to have a “real look” at what it might be like to work and live with children with autism and Asperger syndrome. For more information on CRS’s occupational therapy course, contact Dr. Crowe at tcrowe@salud.unm.edu. ■

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Meet the New Standing Committee

I am proud to introduce the current Standing Committee of the Developmental Disabilities Special Interest Section (DD SIS). We are fortunate to have a breadth and depth of experience represented within this group, as well as a geographic representation across the nation.

Asha Asher, Chairperson of DD SIS, has provided pediatric therapy services over the last 31 years across four countries (the U.S., Canada, Belgium, and India). Currently she works with Sycamore Community Schools in Cincinnati, Ohio, in addition to adjunct teaching.

Terry K. Crowe, Quarterly editor, has been an occupational therapist for 34 years as a practitioner, researcher, and educator. After being on faculty at the University of Washington for 13 years, she founded the Occupational Therapy Program at the University of New Mexico in 1992. She is currently a Professor in the Program after serving as Director for 14 years.

Tracy Jirikowic, Communications Liaison, is Assistant Professor in the Division of Occupational Therapy at the University of Washington. She has been in clinical practice for over 17 years, primarily in the area of pediatrics, and has worked in a variety of practice settings including early intervention, schools, and outpatient specialty clinics.

E. Adel Herge, Research/Education Liaison, has worked as a clinician and educator for 22 years. She is currently Assistant Professor and Department coordinator in the Department of Occupational Therapy at Thomas Jefferson University, and has worked in adult day centers, residential programs (large institutions,

community group homes and family homes) and early intervention both home- and center-based programs.

In terms of publications, Terry leads the way with over 50 peer-reviewed articles and numerous non-peer reviewed articles including a column in *OT Advance* focusing on international issues. Asha, Adel, and Tracy have significant scholarly contributions in terms of publications and have presented internationally and nationally, as well as at the grass roots level.


The team is enriched with international experience. Asha began her occupational therapy career in India and broadened her cultural horizons working in Europe, Canada, and now the U.S. Terry's experience moved in the opposite direction. Starting her career in Iowa, she has worked in Bangladesh, Vietnam, Thailand, and Cambodia, and explored traditional Mexican medicine in Oaxaca, Mexico.

With our clinical experience encompassing Early Childhood (Terry, Tracy), Schools (Asha), Transition to Work (Asha, Adel, Tracy), Adult Care (Adel), Families (Terry, Tracy, Asha, Adel), Technology (Tracy), and Health and Wellness (Adel), paired with our work as researchers and educators, this team is ideally positioned to support the Centennial Vision. Our term promises to be exciting. We will be happy to highlight your innovative work in the field of Developmental Disabilities through our *Quarterly* publications. We invite you to submit articles for the newsletter, either to Terry Crowe at TCrowe@salud.unm.edu, or to me at avasher@yahoo.com. ■

— Asha Asher, MA(OT), MEd (Sp Ed)

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