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Community Partnerships, Home Modifications, and Pediatric Occupational Therapy

■ Tara Delaney, MS, OTR

As a pediatric occupational therapist working both in schools and homes, my approach to services incorporates the family and the community in which the client lives and learns. While in graduate school at the University of Wisconsin—Madison, I had the privilege of participating in an interdisciplinary health-care leadership training program at the Waisman Center. The program brought together a team of occupational therapy, speech therapy, physical therapy, medicine, psychology, and education graduate students to conduct clinical and in-home assessments as well as to develop community-based programs. This experience and the emphasis on community-centered care are forever infused into how I view my profession.

I always believed that my greatest impact was achieved when my efforts were linked with the larger community. When I began a pediatric occupational therapy company called BabySteps a decade ago, I knew that my goal was to grow the company into an interdisciplinary organization that could forge partnerships in the community. BabySteps offers occupational therapy, speech pathology, nursing, and educational psychology services. In the past few years, BabySteps has formed unique relationships with the international adoption community; parent groups; schools; grocery stores; toy stores; and, perhaps most unexpectedly, a behaviorist trained in applied behavior analysis (ABA).

These relationships have been incredibly positive for BabySteps not only in terms of “feeling” more connected to the community, but also in terms of good business practice, an outcome that I did not necessarily predict. The first venture into a more community-based outreach came after the adoption of my daughter from China. My husband and I attended several classes as part of our adoption procedure. We realized that there was an absence of information about early childhood development and how the children’s lack of experiences while in the orphanage awaiting adoption may manifest themselves in physical, emotional, and communication delays. More importantly, parents are left without the knowledge of how they can help their newly adopted child.

I saw this absence of information, coupled with the desire of these parents to ease the transition for their newly adopted child, as my opportunity to give back to the community and, more specifically, to the adoption organization that aided me in achieving my dream of adopting a daughter. We offered a class for expectant parents called Making Sense-ory™ Out of International Adoption and Development. The class explained typical childhood development and the potential impacts when children are not allowed to participate in their occupations of bonding and sensorimotor exploration. In addition, this class

gave me the opportunity to explain occupational therapy to a broader community and the role of occupational therapy practitioners in pediatrics. When I was asked what occupational therapy was, I began with my coined statement, “Occupational therapy practitioners are the ambassadors from the nervous system to function and all that entails.”

The Making Sense-ory™ Out of International Adoption and Development class now uses a team approach with an occupational therapist and a speech-language pathologist. The classes cover sensorimotor development, bonding, and communication as they relate to international adoptions and early experiential deprivation. We give parents ideas for home and family modifications, as well as accommodations. By arming parents with information about what they may see when they bring their child home, they are better prepared to ease the transition for their new child and themselves.

Suggestions for Newly Internationally Adopted Children

We encourage parents to modify the physical environment to suit an infant or toddler who may be coming from an institutional setting, including the usual safety precautions needed for all children. We also stress the need for some social modifications to facilitate the development of parent or family bonding, such as the following:

- *Bathing.* Baths can be traumatic because many children in orphanages have not been immersed in water. We suggest beginning with sponge baths and then moving into a tub with a small amount of water.
- *Exploring the physical environment.* Many children who live in orphanages are not enticed to explore their physical world; instead, their world is brought to them. We suggest encouraging interaction and exploration of the physical environment by placing objects slightly out of reach so that the child learns to physically access his or her environment. We tell parents that they may have to help the child to crawl toward the desired object so that the child understands that if they want something in their environment they have to go to it.
- *Sensory stimulation.* Internationally adopted children must ease into experiences that have a lot of sensory stimulation, such as trips to the mall, birthday parties, and toys that buzz or have flickering lights.
- *Sleeping arrangement.* Many children adopted internationally come from orphanages and sleep in rooms with several other children, so when they begin sleeping in a room by themselves they may have difficulty adjusting to the silence and physical isolation. We suggest playing music from the child’s country of

origin at all times in his or her room. Additionally, if there is another child in the home of a similar age, we suggest the two share a room for the first few months.

- **Communication.** We encourage parents to overemphasize facial expressions and language as they would talk to an infant.
- **Bonding time.** We suggest that parents request that nonimmediate family members and friends give the family and the newly adopted child some uninterrupted bonding time.
- **Physical contact.** Being held for long periods can be an adjustment for children who have not been exposed to this intense sensory input. We encourage parents to ease into holding if the child seems uncomfortable.
- **Basic sign language.** To promote quick communication, we suggest that parents learn some basic signs for words such as *eat, drink, sleepy, bath, and love*, and to begin communicating with their child right away.

therapy practitioners who are seeing a child for 1 to 3 hours a week to integrate sensory and motor strategies effectively and efficiently during the child's ongoing ABA treatment sessions.

Home Modifications for Children With Autism

Children with autism benefit most when the therapies they receive are administered as consistently as possible (Exkorn, 2005). By creating an environment that allows parents and caregivers to easily implement sensory integration strategies and ABA techniques in the home setting, consistency is more likely to occur. In my experience working in homes, parents and caregivers seem to be receptive of therapeutic recommendations when the activities are not “therapy like.” The following are some home modification ideas that incorporate both occupational therapy and ABA strategies.

Make sure that the sensory environment is conducive to the individual child. For children who are overstimulated by visual input:

- Dim the lights.
- Decrease visual clutter.
- Use the environment or materials to indicate the beginning and end of the activity. For example, for a cooking activity, make sure each step is placed in sequential order and when each step is completed, place the materials in a bucket.
- Have only the items in view that you are using, arranging them in a first-to-last sequence, and a symbol for *reward*. After completing activities, let the child choose the reward from a set of pictures.
- Use a first/then card when working on a nonpreferred or difficult activity. On white cardboard, draw two boxes and write the words “First” (on the left) and “Then” (on the right) below each box. In the left box, place a simple word or picture that indicates a nonpreferred activity (e.g., “bath”). In the right box, place a word or picture indicating something the child enjoys (e.g., “snack”).
- Because children with autism are visual learners and have difficulty with working memory, use pictures in the home to help them understand their environment better and communicate more effectively. For example, place magnetic pictures (or photos with magnets) with the written name of a food under it—such as milk, fruit, cheese, or juice—onto the refrigerator so the child can pull off the wanted item and give it to the caregiver, thus decreasing communication frustration. The written name reinforces language development. This strategy also can be used on the outside of a closet or toy bins and on objects, including the television, bed, and bathtub.
- Use a picture schedule to communicate a routine (Bondy & Sulzer-Azaroff, 2002) such as brushing teeth, and provide a picture of each step through digital pictures or premade pictures from programs such as BoardMaker or Picture Exchange Communication System (Frost & Bondy, 2002).

Community-Based Services for Children With Autism

In April 2006, at the Autism Spectrum Disorders Workshop sponsored by First Five of California, I spoke on the importance of sensory integration strategies when working with children with autism spectrum disorder. Another speaker at the same conference was Hilary Baldi, MA, who cofounded the Behavioral Intervention Association, a not-for-profit organization in San Francisco. She made a strong case for ABA within the context of play and its potential for helping children with an autism spectrum condition (Baldi, 2000). ABA is the basis of many teaching applications and curricula used in both traditional and special education classrooms (Schetter, 2006). As I listened to Ms. Baldi's presentation, I realized the correlation between the goals of ABA and occupational therapy. We both determine a child's learning and behavior strengths as well as weaknesses. Based on a profile of strengths and weaknesses, occupational therapists and behaviorists provide interventions that promote learning and adaptive behavior while also teaching adaptive strategies.

After Ms. Baldi's presentation, we talked about the best way to serve children with autism. Without realizing it, we had “sold” each other on two seemingly different approaches and realized how powerful linking occupational therapy and ABA could be. As I mentioned earlier, occupational therapy practitioners are the ambassadors between the nervous system and function, and ABA is a systematic language that we ambassadors can use to facilitate nervous system change and improve function for children with autism.

The need for interdisciplinary teamwork is paramount when working with children and families, especially for children with autism (Greenspan & Wieder, 1998). Occupational therapy professionals must understand what techniques are most effective for teaching the child new skills as well as what skills the ABA team is working on in the home. Because a child with autism may receive ABA therapy up to 40 hours per week (Richman, 2001), this partnership is a great way for occupational

Increasing Visibility Within the Community

The following are some of the ideas that BabySteps has used to make our services known in the community:

- Set up a table at organic supermarkets or baby stores when they conduct community health fairs. Health fairs are opportunities to contact large numbers of potentially interested clients. Distribute brochures on how to provide a rich sensory environment for a new infant or anything else that would appeal to this population.
 - Offer to teach an individual class in a course for future teachers, nurses, and child psychology majors at local colleges.
 - Offer to speak to a local mothers group or other community organizations.
 - Attend non-occupational therapy conferences or workshops in areas of interest and network with other related professionals.
- Connecting with others in the community through professional partnerships has proven to be professionally enriching and beneficial

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for my company, and I believe that the influence of other professions has greatly enriched my effectiveness as a therapist to the families I serve. ■

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Finding Evidence for the Effectiveness of Occupational Therapy Interventions

■ Jessica Scheer, PhD, and Ann O'Sullivan, OTR/L, LSW

Maria, an occupational therapist who has worked in dementia care for almost 20 years, was asked to give a presentation to a local group of physicians and case managers on how occupational therapy interventions can improve the well-being of persons with dementia and their family caregivers. Knowing that physicians need to hear solid and recent evidence about the effectiveness of occupational therapy interventions if they are to make appropriate referrals, Maria was eager to find the best available evidence. She turned to the American Occupational Therapy Association's (AOTA's) Web site (www.aota.org) to explore relevant information and resources.

The primary goals for clients with dementia are to enhance their autonomy and performance of activities of daily living (ADL) and to maintain their well-being and quality of life as well as that of their family caregivers (Dooley & Hinojosa, 2004). Maria began the evidence-based practice (EBP) process by developing a clinical question: "What is the evidence that occupational therapy interventions effectively meet these goals?"

From the AOTA Web site, Maria accessed the EBP Resource Directory and clicked on the subsection, Bibliographic Databases. There she located the National Library of Medicine's database, PubMed, and clicked on its special search filter service, PubMed Clinical Queries. Using the key words *occupational therapy and dementia*, Maria found many relevant citations, including randomized control trial (RCT) studies, systematic reviews of the literature, consensus articles, and practice guidelines. (See "Other Resources" at the end of this article.) Looking through the abstracts, she quickly learned that her presentation audience used the term *nonpharmacological interventions* to discuss any environmental or behavioral intervention for clients with dementia. This insight provided Maria with an important entrée to her audience from which she could easily segue into discussing the occupational therapy interventions with positive outcomes as evidenced by research findings.

Maria narrowed the group of abstracts and selected 10 to look at more closely. Some of the abstracts were linked to their full text in

PubMed Central; full-text versions of others could be found through university online subscription-based resources; OTSearch; or elsewhere on the Internet, such as BioMed Central (www.biomedcentral.com), Directory of Open Access Journals (www.doaj.org), Find Articles (www.findarticles.com), or HighWire Press (<http://highwire.stanford.edu>). She then selected four RCT studies to be the core of her presentation along with a systematic review, a practice guideline, and an AOTA publication based on a program used in several of the studies (Gitlin & Corcoran, 2005).

In the first study Maria reviewed, a team of occupational therapy researchers conducted an RCT to determine the effectiveness of home environmental modifications and family caregiver training to decrease ADL dependence and reduce caregiver distress (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001). Over 12 weeks, clients and their caregivers in the intervention group received five 90-minute education, physical, and social environmental-modification sessions. Caregivers were given guidance to develop realistic appraisals of the caregiving situation and dementia-related behaviors and to simplify their home environments. As a result, the intervention group reported significantly fewer declines in clients' instrumental ADL performances, less decline in self-care, and fewer behavior problems than those in the usual care control group. The family caregivers in the intervention group also reported significantly enhanced self-efficacy in managing problematic behaviors than those in the control group. In the second and third studies, the researchers reported similar results to the Gitlin et al. (2001) study, extending assessment first to 6 months and then to 12 months after intervention (Gitlin et al., 2003; Gitlin, Hauck, Dennis, & Winter, 2005).

In the last article Maria reviewed, occupational therapy researchers from the Netherlands conducted an RCT to determine the effectiveness of environmental and behavioral interventions to increase performance of ADL for clients with dementia and perceived role competence among family caregivers (Graff et al., 2006). Over 5 weeks, clients and their caregivers received 10 at-home sessions, with assessments at 6 and 12 weeks after intervention. Clients were trained to use compensatory and environmental strategies to perform ADL; family caregivers were trained to supervise and assist clients and to reframe behavioral problems in an environmental perspective. Client ADL performance and caregivers' perceived role competence improved at 6 weeks and remained so at 12 weeks.

Summary

With this evidence, Maria prepared the content for her presentation. She was confident that she would be able to convey the benefits of occupational therapy interventions to her audience, stressing the importance of addressing the needs of the client with dementia as well as those of the family caregivers. She was optimistic that the physicians would begin to refer more clients for occupational therapy services, and she planned to read more about the EBP program implemented in the studies. ■

Note. By early 2008, an Evidence-Based Literature Review of Occupational Therapy Interventions for Persons With Alzheimer's Disease will be posted in the Evidence-Based Resources Section of the AOTA Web site (www.aota.org). This review will be presented as Critically Appraised Topics (CATS) and Critically Appraised Papers (CAPS) and will summarize the evidence and highlight the application to practice.

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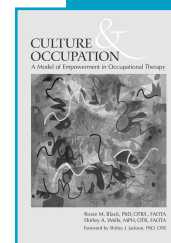
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