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Occupational Therapy: Meeting the Needs of Families of People With Autism Spectrum Disorder

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MeSH TERMS

- child development disorders, pervasive
- health services needs and demands
- family health
- occupational therapy
- professional role



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Occupational therapy has much to offer to families of people with autism spectrum disorder (ASD). However, people outside the profession may be unaware of occupational therapy's breadth and scope. It is our responsibility and our duty to express the full range of occupational therapy services through research, clinical practice, advocacy, and consumer education. This special issue of the *American Journal of Occupational Therapy*, with its focus on autism, embarks on this endeavor by highlighting research and theoretical articles that address the various aspects of occupational therapy practice that can help to fully meet the needs of people with ASD and their families.

Kuhaneck, H. M., & Watling, R. (2015). Guest Editorial—Occupational therapy: Meeting the needs of families of people with autism spectrum disorder. *American Journal of Occupational Therapy*, 69, 6905170010. <http://dx.doi.org/10.5014/ajot.2015.019562>

The prevalence of autism spectrum disorder (ASD) continues to increase, with current reports suggesting that 1 in every 68 children will be diagnosed with ASD (Centers for Disease Control and Prevention, 2014). Although the cause of this increase is a controversial and much-debated topic (Chaste & Leboyer, 2012; Matson & Kozlowski, 2011), the outcome is quite clear: Families need assistance (Karst & Van Hecke, 2012). Children with ASD experience a range of difficulties, such as limited social skills and understanding of social rules and conventions, inflexibility and adherence to familiar routines, restricted interests or repetitive behaviors, and hyper- or hyporeactivity to sensory experiences (American Psychiatric Association [APA], 2013), all leading to impairments in everyday social and occupational functions that affect family life.

In recent years, the U.S. government has responded to this potential public health crisis with a significant increase in grant funding for ASD research; however, most of the resultant studies have focused on basic science in the hopes of finding a cure (Singh, Illes, Lazzeroni, & Hallmayer, 2009; see *Autism Speaks*, 2012, 2014). This focus has been hotly debated, with many from the neurodiversity movement vocally condemning the search for a cure and expressing their belief that ASD should be accepted and accommodated for within society (see, e.g.,

the Autistic Self Advocacy Network website, <http://autisticadvocacy.org/>). People with ASD are more likely to view the neurodiversity movement positively (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013), and proponents of this view suggest that the billions of dollars being spent on research would be better spent on services that help people. No matter on which side of that debate one lands, for people currently living with ASD, the discussion of some future cure is moot and does not address current needs. Although intervention research has increased (Singh et al., 2009), there is still a relative paucity of literature to support effective evidence-based practice. Research to identify which of the myriad proposed interventions are effective is a pressing need.

People with ASD and their families require a variety of services and interventions, and families report significant service needs that often go unmet (Vohra, Madhavan, Sambamoorthi, & St. Peter, 2014). Children may receive all three primary developmental therapy services—occupational therapy, physical therapy, and speech–language pathology—as well as the assistance of a behaviorist and special education programs (Bowker, D'Angelo, Hicks, & Wells, 2011; Goin-Kochel, Myers, & Mackintosh, 2007; Interactive Autism Network [IAN], 2011). Some families pursue nutritional assistance, a variety of specialized leisure services, and alternative

and complementary therapies (Bowker et al., 2011; Christon, Mackintosh, & Myers, 2010; IAN, 2011; Perrin et al., 2012). Funding for these services varies considerably across the country, and families are often saddled with enormous expenses for care (Buescher, Cidav, Knapp, & Mandell, 2014; Parish, Thomas, Rose, Kilany, & Shattuck, 2012). Families report that they need more information (Osborne & Reed, 2008), but their sources of information are at times ill informed, incomplete, or not based in evidence (Mackintosh, Myers, & Goin-Kochel, 2005; Stephenson, Carter, & Kemp, 2012). In the United States, debate continues over which services are most effective and which should be covered by insurance, often leaving parents in a quandary over how to proceed and how to help their child.

Awareness and Knowledge of Occupational Therapy

Occupational therapy practitioners are regularly recognized as part of the team providing services for people with ASD (Volkmar et al., 2014). However, the role recommended for practitioners often focuses on sensory or motor skills. For example, at a recent conference devoted to ASD, multiple professionals from other professions mentioned occupational therapy practitioners as the experts for sensory concerns (Autism Speaks, 2013). In research studies, families often report coming to occupational therapy to address sensory issues and challenges with self-regulation (Cohn, Kramer, Schub, & May-Benson, 2014; IAN, 2011), and parents report that they are happy with the progress from occupational therapy in relation to sensory-motor issues in particular (Mackintosh, Goin-Kochel, & Myers, 2012, pp. 54, 56). With the addition of sensory difficulties to the diagnostic criteria in the current, fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (APA, 2013) and new research suggesting a link between infant sensory perception and the emergence of ASD symptoms (Autism Speaks, 2015; Gliga, Bedford, Charman, & Johnson, 2015; Gliga, Jones, Bedford, Charman, & Johnson, 2014), occupational therapy practitioners may become

even more highly recognized for their knowledge and skills in addressing these needs (Whitney & Miller-Kuhaneck, 2012). However, occupational therapy offers far more than solutions for sensory-motor concerns.

Although currently no research has documented general knowledge of occupational therapy services, it is likely that when families first begin receiving services, they know little about what to expect or about the differing roles of the various professionals on the team (Woods & Lindeman, 2008). Parents may seek information about occupational therapy in a variety of places, including the World Wide Web. In their searching, parents may stumble on reliable and accurate information or they may just as easily come across statements such as “occupational therapists in the educational field often work on fine motor control, such as handwriting” (Vann, 2010, para. 2). How are parents to know all that occupational therapy practitioners are able to help them with if their searches for information do not result in clear descriptions of the domain of occupational therapy practice? If parents or other professionals describe occupational therapy practitioners only as sensory-motor experts, it is our responsibility to correct this misperception in any way we can.

The *Occupational Therapy Practice Framework: Domain and Process* (American Occupational Therapy Association, 2014) defines the domain of practice of the profession. Occupational therapy’s domain encompasses those areas that parents of children with ASD, and research reports, tell us create the most difficulty in daily life situations for children, teens, and adults with ASD: play, social participation, sleep, family routines, independent living, and employment (Boyd, McCarty, & Sethi, 2014; Jang, Dixon, Tarbox, & Granpeesheh, 2011; Kasari, Chang, & Patterson, 2013; Magiati, Tay, & Howlin, 2014; Shattuck et al., 2012; Sivertsen, Posserud, Gillberg, Lundervold, & Hysing, 2012). Occupational therapists have expert knowledge and skills in addressing these areas of occupational performance, including the contextual factors that influence performance, and they use a holistic view of the

person and all of his or her interrelated systems and functions. Thus, the profession of occupational therapy, with its broad scope and focus, offers families numerous possibilities for assistance. The distinct value that the profession of occupational therapy provides to families of people with ASD is its holism. However, occupational therapy’s holistic approach is not always clearly documented or modeled for those outside the profession.

State of Our Research

To better understand the perceptions others likely have of occupational therapy, it is helpful to examine the topics addressed in the literature. A search of the occupational therapy-specific database OT Search, although not a perfect measure, is generally illuminating. Within OT Search, a search for the term *autism* found 333 records. When the word *sensory* was added to the search terms, the search identified 133 of those 333 records, suggesting that perhaps approximately 40% of the literature on autism in primary occupational therapy sources has to do with sensory-related concerns. A search on *autism* and *motor* found 50 articles; *autism* and *play* led to 35 (of which quite a few were also related to sensory-motor concerns). *Autism* and *self-care* returned 9 articles (of which 3 were related to sensory-motor relationships with self-care), and *autism* and *family routines* returned just 6. A search on *autism* and *family goals* found 2 records, and one on *autism* and *sleep* located 3, all related to occupational therapists’ ability to help with sleep issues using sensory integration theory and principles. A parallel search run in PubMed found similar patterns (*occupational therapy* and *autism* resulted in 298 records; *occupational therapy, autism*, and *sensory*, 108; but *occupational therapy* and *sleep*, only 6, and *occupational therapy* and *feeding* just 8). The professional literature of occupational therapy clearly needs to better document occupational therapy’s holism through published research.

State of Our Practice

The information about practice patterns in occupational therapy for children with autism in the United States is now quite dated (Case-Smith & Miller, 1999; Watling, Deitz, Kanny, & McLaughlin, 1999). However, both Case-Smith and Miller (1999) and Watling et al. (1999) found that occupational therapy practice for children with ASD had a heavy reliance on Ayres Sensory Integration[®] theory, perhaps in part because practitioners reported feeling competent in this intervention approach. In a more recent survey from Australia (Ashburner, Rodger, Ziviani, & Jones, 2014), a continued focus on sensory integration was reported in practice. Although the contributions of a sensory approach to intervention are widely recognized as important (Autism Speaks, 2013; Filipek et al., 2000; Volkmar et al., 2014) and are often credited for making a significant difference in a family's daily experiences (Cohn, 2001; Schaaf, Hunt, & Benevides, 2012), other occupational therapy practices may be equally as helpful. However, families may not realize that the occupational therapy practitioner is able to address their wider range of needs.

Call to Action

Principles of family-centered care (FCC) suggest that occupational therapy practitioners work as partners with families in addressing their goals and priorities rather than the therapist's goals (Kuo et al., 2012). FCC is considered best practice and an important method in promoting positive outcomes related to family functioning (Dunst, Hamby, & Brookfield, 2007; Kuo et al., 2012). An occupational therapist can provide assistance with many of the commonly reported challenging behaviors in ASD, such as escapism, inappropriate sexual behaviors, and poor object play (Jang et al., 2011; Kuhaneck & Britner, 2010), through basic occupational therapy processes of task analysis, task-environment modification and adaptation, and client-family education practices.

How are families to learn about occupational therapy's scope of practice? One way is for therapists to provide such in-

formation while they gather information during the evaluation process (Woods & Lindeman, 2008). As therapists ask family members questions and seek to determine family goals, they can explain why they are asking and discuss the full scope of occupational therapy practice. The field has an unprecedented opportunity to expand its perceived role in work with families by educating families about its scope, documenting its efficacy, and working toward goals that are important to families. Research documenting the use of FCC in occupational therapy interventions with people with ASD is currently limited. Although this literature base is growing, outside influences often work to make FCC difficult to provide, and artificial boundaries may be placed around occupational therapy practice. When we yield to external pressures and become reductionistic, we lose some of the power of our profession.

Recognizing the gap between what occupational therapy is able to do and others' perceptions of what occupational therapy can do is a call to action. Others in the autism field are stressing the importance of meaningful participation (Carbone, 2013). To best meet clients' needs and provide services that families of children with ASD desperately need, occupational therapy practitioners must educate families and other professionals about occupational therapy's scope of practice and its distinct value, understand the evidence and effectively use evidence-based methods and sound scientific processes in practice, explain the occupational perspective and value of occupational therapy services in achieving client goals and priorities, and advocate for improved funding for occupational therapy services.

In This Issue

In this issue, we provide literature that demonstrates the breadth of occupational therapy services and ways in which the profession is seeking to provide FCC. The articles presented in this issue aim to expand the public perspective on occupational therapy practice by highlighting the breadth of occupational therapy practitioners' knowledge and skills. Four systematic reviews

(Kuhaneck, Madonna, Novak, & Pearson, 2015; Tanner, Hand, O'Toole, & Lane, 2015; Watling & Hauer, 2015; Weaver, 2015) evaluate the literature published from 2006 to early 2013 regarding interventions within the scope of occupational therapy practice to address key aspects of behavior and performance in people with ASD and their impact on family functioning. Heathcock, Tanner, Robson, Young, and Lane (2015) present findings regarding knowledge and understanding of body functions and performance skills such as motor development. Other articles (Bodison, 2015; Tomchek, Little, & Dunn, 2015; Zobel-Lachiosa, Andrianopoulos, Mailloux, & Cermak, 2015) relate underlying body functions to higher level performance, such as activities of daily living and play. Still others represent an attempt to focus services on the specific needs identified by families (Schaaf et al., 2015) as well as on cultural perspectives that expand understanding of the values families hold and how these families interact with Western service delivery systems (Blanche, Diaz, Barretto, & Cermak, 2015; Santoso, Ito, Ohshima, Hidaka, & Bontje, 2015). In addition, we include two articles (Swinth, 2015; Tomlin, 2015) that highlight the contributions of various research methodologies in ensuring that occupational therapy practitioners consider all ways of knowing and sources of evidence as they strive to understand the lived experiences and needs of families of children with ASD and the effectiveness of various interventions in meeting these needs.

As guest editors, we sincerely thank all of the authors for their contributions; all of the families and individuals with whom we have worked, who have taught us more than they know; and our occupational therapy mentors, Jane Case-Smith and Jean C. Deitz. Without their guidance and encouragement, we would not have been writing this editorial. ▲

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