Frequently Asked Questions (FAQ)

What is Occupational Therapy's Role in Supporting Persons With an Autism Spectrum Disorder?

1. What information about Autism Spectrum Disorders will help guide practice?

Autism Spectrum Disorders (ASDs) are a group of developmental disabilities that can cause significant social, communication, and behavioral challenges. According to the most recent statistics from the Centers for Disease Control (CDC), autism is four times more likely to occur in males than females and affects an average of 1 in 110 children in the United States (2009).

The Diagnostic and Statistical Manual IV (DSM IV) categorizes ASDs into three types within a continuum:

- **Autistic Disorder** (also called "classic" autism)
  This is what most people think of when hearing the word "autism." People with autistic disorder usually have significant language delays, social and communication challenges, and unusual behaviors and interests. Many people with autistic disorder also have intellectual disability.
- **Asperger Syndrome**
  People with Asperger syndrome usually have milder symptoms of autistic disorder. They might have social challenges and unusual behaviors and interests. However, they typically do not have delays with language or intellectual disability.
- **Pervasive Developmental Disorder–Not Otherwise Specified** (PPD-NOS; also called "atypical autism")
  People who meet some of the criteria for autistic disorder or Asperger syndrome, but not all, may be diagnosed with PDD-NOS. People with PDD-NOS usually have fewer and milder symptoms than those with autistic disorder. For example, they may have only a social impairment.

Recently, the phrase *autism spectrum disorder* has been used in the literature to refer collectively to people with one of these diagnoses. The three types of ASDs referred to in the DSM-IV are useful when referring to characteristics or research findings that are pertinent to a specific diagnostic group.

People on the autism spectrum face significant challenges in 1) social interaction, 2) verbal and nonverbal communication, and 3) stereotypic behaviors or interests. In addition, they will often have unusual responses to sensory experiences, such as touch, sound, or smell. Each of these

symptoms ranges from mild to severe and presents in each individual differently

While the causes of ASDs are not known, there are many components hypothesized to make a child more likely to have an ASD, including different environmental, biological, and genetic factors. Early diagnosis is critical, and many recent research studies have focused on early indicators of ASDs in very young children.

According to the Autism Society of America (ASA 2010), some early signs that may suggest an ASD are:

- Lack of or delay in spoken language
- Repetitive use of language and/or motor mannerisms (e.g., hand-flapping, twirling objects)
- Little or no eye contact
- Lack of interest in peer relationships
- Lack of spontaneous or make-believe play
- Persistent fixation on parts of objects

Detection or determination of an ASD is based on observation of the individual's communication, behavior, and developmental levels using standardized testing including the Autism Diagnostic Interview (Rutter, LeCoutear, & Lord, 2003) and the Autism Diagnostic Observation Schedule-Revised (Lord, Rutter, DiLavore, & Risi, 2002) which together are the gold standard for diagnosis. Diagnosis also includes gathering input, developmental history, and current behavioral descriptions from parents and other caregivers. Often, medical testing is used to rule out other diagnoses that may present with similar symptoms. ASDs can sometimes be identified at 18 months of age or earlier. By the age of 2,

diagnosis by an experienced professional can be considered very reliable. The CDC recommends that all children be screened specifically for ASDs during well-child check-ups at 18 and 24 months and even more carefully if the child is considered high risk for developmental disabilities. The American Academy of Pediatrics also endorses early and continuous surveillance and screening for ASDs. (CDC, 2010). Occupational therapy practitioners can be instrumental in helping to identify the early signs suggestive of an ASD.

Young children on the autism spectrum often have difficulty participating in appropriate play, meeting developmental milestones, communicating effectively with others, making and keeping friends and conforming to expected behavioral norms. School-age children frequently need special education supports and services to benefit from their educational program. As adults, many continue to need some support with housing, employment, and community integration, while some may not be able to live independently or hold a job. It is important to build a community of supports including family, friends, neighbors, and other community members who can assist the adult with an ASD to be successful.

An ASD diagnosis affects not only the person diagnosed, but also the entire family. Parents and caregivers are faced with many stressors, including difficulty obtaining an appropriate diagnosis for their child, making decisions about intervention and educational planning, coping with financial strain, grief, and managing daily behavioral challenges, some of which may be due to unusual responses to sensory stimuli. Marital relationships can become strained, and siblings may feel neglected or resentful of the attention given to the child with an ASD.

2. What is the role of occupational therapy in working with persons with an ASD? What types of services are provided?

The domain of occupational therapy is "...supporting health and participation in life through engagement in occupation…The broad range of activities or occupations are sorted into categories called 'areas of occupation'—activities of daily living, instrumental activities of daily living, rest and sleep, education, work, play, leisure, and social participation (AOTA, 2008)."

Occupational therapy practitioners provide services to individuals with an ASD through a variety of service delivery models including direct service, consultation, group intervention, and community-based services. In addition, occupational therapy practitioners participate in education and advocacy activities at persons, organizations, and population levels. More specifically, the role of occupational therapy is to:

- **Evaluate** the individual's skills and level of functioning in activities and contexts relevant and meaningful to the individual.
- **Assess** the individual's strengths and areas for improvement that should be addressed through intervention.
- **Identify** the impact of the ASD on the individual's functioning and ability to carry out relevant daily life activities and occupations.
- **Provide** individualized therapy services that are tailored to the person's identified areas of need and that maximize the individual's skills and performance. Therapy services may include occupation-based intervention, purposeful activity, and preparatory methods (AOTA, 2008).
- **Support** the individual and their family members in coping with the challenges of living with an ASD.
- **Adapt or modify** activities, environments, and contexts to support performance and participation in everyday life situations and settings.
- **Collaborate** with the client, family members, other service providers, and other key people in the individual's life to ensure that services are focused on meaningful and relevant occupations and contexts.

Occupational therapy interventions for persons with an ASD are designed in response to individual evaluation data using evidence-based practices that emphasize development of skills and abilities that will help the individual achieve their desired outcomes (AOTA, 2008). For individuals with an ASD, the scope of occupational therapy services across the life course may include regulation of emotional and behavioral responses; processing of sensory information necessary for participation; development of social abilities, interpersonal skills and peer relationships; self-management skills such as dressing, feeding, hygiene, and sleep; skills needed for success in school such as organization of task materials, independent work skills, and group process abilities; assistive technology for accomplishing communication, school, or work functions, and more (AOTA, 2010).

In addition, occupational therapy practitioners provide services to caregivers including strategies for stress and anxiety management, caring for the individual with an ASD and balancing life responsibilities. Occupational therapy services can also be provided surrounding significant life events such as birth of a sibling, moving to a new home, transition into or out of school, and seeking, obtaining, and maintaining employment.

3. What are some examples of occupational therapy evaluation and intervention for individuals with an ASD?

Occupational therapy evaluation consists of conducting an occupational profile and analysis by gathering information regarding the individual's strengths, abilities, desires, interests, and limitations affecting occupational performance.

The therapist synthesizes the information through observation, assessment, and interpretation of the data collected in order to develop goals, intervention plans, and approaches based on clinical judgment, knowledge, and skills as well as evidence-based practices and models.

Occupational therapy intervention incorporates therapeutic use of self and therapeutic use of occupations and activities. Occupational therapists design occupation-centered activities that consider the environments and contexts in which activities or occupations are performed, the demands of the activities, and the factors within the client. Interventions also include consultation, education, and/or advocacy. The overarching outcome of intervention is focused on supporting health and participation in life through engagement in occupation (AOTA, 2008). *Definitions provided in this section are from the AOTA (2008).*

Evaluation

Examples

- Conduct a skilled assessment to determine the person's ability to interpret, integrate, and respond to sensory input as a foundation for functioning in various contexts and environments
- Assess potential community worksites for employment training of transitioning students
- Assess occupations and/or performance skills such as self care (ADL), gross motor, fine motor, perceptual, visual-motor, and social skills

Therapeutic use of self, occupations, and activities

A practitioner's planned use of his or her personality, insights, perceptions, and judgments; AND occupations and activities are selected for specific clients that meet therapeutic goals

Examples

- Provide client-centered intervention to address individual needs for skill development in motor, cognitive, perceptual, play, and social skills
- Provide direct intervention to help individuals develop skills and abilities, learn compensatory methods, and build effective social, behavioral, and participation strategies.
- Provide sensory activities to prepare for participation in daily life including self care, recreational, educational, or vocational activities
- Design sensory stories and/or visual prompts to support a child's ability to focus attention, stay on task and adapt to changes in routine
- Develop strategies for parents and/or caregivers to promote success in homework completion
- Design a structured activity with a peer in collaboration with a playground monitor to promote social interaction during recess
- Develop extracurricular clubs, activities, sports/fitness programs that are supportive and inclusive
- Develop and implement a social group for adolescents in collaboration with a speech-language pathologist
- Modify work tasks and/or environments to fit to the individual's needs and abilities at a place of employment

Consultation

Using knowledge and expertise to collaborate with the client. The collaborative process involves identifying the problem, creating possible solutions, trying solutions, and altering them as necessary for greater effectiveness. When providing consultation, the practitioner is not directly responsible for the outcome of the intervention

Examples

- Review curriculum with educators and recommend strategies to promote attention, concentration, and participation. For example, intermittent breaks from schoolwork and/or physical activity may enhance learning.
- Recommend modifications to the home, classroom, or work environment such as designing a "quiet space" for calming
- Advise on community-based older adult programs to accommodate adults with an ASD
- Collaborate with a psychologist and classroom teacher to design strategies and methods for addressing sensory, behavioral or daily living challenges for a child with an ASD.

Education

Imparting knowledge and information about occupation, health, and participation that does not result in the actual performance of the occupation/activity

Examples

- Recommend changes to the general school environment as part of district strategic planning committees. For example, providing pictorial cues for environment-specific behavior expectations (classroom, bus, hallway, cafeteria, recess, assemblies)
- Prepare and provide tip sheets, in-service training and on-line information to support IEP team in planning for meaningful learning experiences in a variety of curriculum subjects and social areas
- Enhance partnerships between clinic-based and school-based OTs serving individuals on the spectrum
- Instruct employers about the strengths and abilities of workers on the autism spectrum to promote greater awareness

Advocacy

Efforts directed toward promoting occupational justice and empowering clients to seek and obtain resources to fully participate in their daily life occupations.

Examples

- Serve on a policy board of an organization that promotes support groups for siblings, parents, and individuals on the autism spectrum
- Participate in a school board committee to develop anti-bullying programs
- Advocate to programs and agencies serving adults to consider programming to meet the needs of adults on the autism spectrum
- Build relationships with community businesses, policy makers, and legislative leaders to improve awareness of the strengths and abilities of individuals on the autism spectrum

4. What is the evidence for effective interventions for individuals with an ASD?

There is a growing body of evidence both within and outside occupational therapy that can be used to guide both training of professionals working with individuals with autism spectrum disorders and selecting of appropriate interventions.

Current research indicates that there are certain elements shared by effective interventions. These findings/results continue to support the characteristics first identified by the National Research Council in the book, *Educating Children with Autism* (2001) and again identified in the *AOTA Occupational Therapy Practice Guidelines for Children and Adolescents with Autism* (Tomchek & Case-Smith, 2009). These characteristics include:

1. Intervention begins early;
2. Intervention is intensive in hours;
3. Families are actively involved in their child's intervention;
4. Staff are highly trained and specialized in autism;
5. Intervention is carefully planned and research-based including plans for generalization and maintenance of skills

AOTA conducted a systematic review on interventions used in or of relevance to occupational therapy in children and adolescents with autism spectrum disorder (Case-Smith & Arbesman, 2008) and the findings were incorporated into the *AOTA Occupational Therapy Practice Guidelines for Children and Adolescents with Autism* (Tomchek & Case-Smith, 2009).

There is a growing body of evidence examining outcomes of occupational therapy using a sensory integrative approach for individuals with an ASD. An evidence-based review conducted by Schaaf (2010) concluded that "there is emerging evidence to support the use of the sensory integrative approach for individuals with an ASD and in particular to impact sensory and motor outcomes and individually identified client-centered goals…but that more research is needed."

Behavioral interventions are effective in reducing problem behaviors, and enhancing language and communication as well as performance in daily living. Additionally, the use of visual cues and schedules, as seen in TEACCH and the Picture Exchange Communication System, can teach an individual with autism a compensatory skill that has application across the lifespan in multiple settings such as school and employment.

Developmental approaches to intervention for individuals with autism have a growing body of supporting evidence. These approaches tend to have an impact on language, communication, social-emotional skills, joint attention and symbolic, purposeful play. Furthermore, studies support the effectiveness of engaging parents through coaching and education in their child's intervention and current research

shows that "parent-mediated intervention can be as effective as therapist-directed sessions." An occupational therapy practitioner may benefit from training in these techniques as they are a good philosophical match in that they engage the child using naturally occurring learning opportunities (Tomchek & Case-Smith, 2009).

Relationship-based interventions are designed to address the core deficits of autism of difficulty with socialization and development of relationships. The studies on developmental, individual difference, relationship-based (DIR) model and other approaches suggest that parents should be involved in the child's intervention and promote the use of coaching methods for parent education and engagement. Occupational therapy practitioners may use child engagement strategies and a parent coaching model within their service plan which aligns with a DIR model.

Best practice dictates that occupational therapy practitioners use evidence-based decision-making and that they seek the necessary education and training to effectively incorporate these methods into their occupation-based interventions with individuals with an ASD and their families.

5. Where can I find more information/related readings/resources?

The selected resources listed below have a national focus and use the growing evidence-based research in their service delivery and publications.

Organizations and Networks

- Autism Information: www.hhs.gov/autism/
- Autism Research Network www.autismresearchnetwork.org/AN/
- Autism Society of America: www.autism-society.org
- CDC Learn the Signs: Act Early campaign www.cdc.gov/ncbddd/actearly/index.html
- Centers for Disease Control and Prevention (CDC) www.cdc.gov/ncbddd/autism/index.html
- Easter Seals www.easterseals.com/site/PageServer?pagename=ntlc8_autism_service
- Interactive Autism Network (IAN): www.ianproject.org/
- National Institute of Mental Health (NIMH) www.nimh.nih.gov
- Ohio Center for Autism and Low Incidence (OCALI) www.ocali.org/view.php?nav_id=9
- Organization for Autism Research: www.researchautism.org/
- The PDA Center: Professional Development in Autism http://depts.washington.edu/pdacent/

Law and Safety

- Dennis Debbaudt's Autism Risk & Safety Management www.autismriskmanagement.com
- Wright's Law: www.wrightslaw.com

AOTA Resources

- American Occupational Therapy Association (2007). AOTA Evidence Briefs: Autism Spectrum Disorder 9. Effectiveness of a Home Program Intervention for Young Children with Autism.
- American Occupational Therapy Association (2007). AOTA Evidence Briefs: Autism Spectrum Disorder 12. Relationship-focused Early Intervention with Children with Pervasive Developmental Disorders and Other Disabilities.
- American Occupational Therapy Association (2007). AOTA Evidence Briefs: Autism Spectrum Disorder 6. Randomized Trial of Intensive Early Intervention for Children with Pervasive Developmental Disorder.
- American Occupational Therapy Association (2007). AOTA Evidence Briefs: Autism Spectrum Disorder 1. Efficacy of Sensory and Motor Interventions for Children with Autism.
- American Occupational Therapy Association (2010). The scope of occupational therapy services for individuals with an autism spectrum disorder across the life course. *American Journal of Occupational Therapy*, in press)
- AOTA (2009) Response to National Standards Report http://www.aota.org/Educate/Research-Advocacy/2009-Statements/Standards.aspx
- AOTA (2010). Autism resources. Retrieved February 2010 from http://www.aota.org/autism. Microsite includes resources such as tip sheets, fact sheets, policy statements, and articles
- Case-Smith, J., Arbesman M. (2008). Evidence-Based Review of Interventions for Autism Used in or of Relevance to Occupational Therapy. *American Journal of Occupational Therapy, 62*, 416–429.

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- Jackson, L.L., Arbesman, M. (eds.) (2005). *Occupational therapy practice guidelines for children with behavioral and psychosocial needs*. Bethesda, MD: AOTA Press
- Miller-Kuhaneck, H. & Watling, R. (2009) *Autism: A Comprehensive Occupational Therapy Approach, 3rd Edition*. Bethesda, MD: AOTA Press.
- Scott, J.B. (2006). American Occupational Therapy Association Fact Sheet: Occupational therapy's Role with Autism. Bethesda, MD: American Occupational Therapy Association, Inc.
- Tomchek, S.D & Case-Smith. J. (2009). *Occupational Therapy Practice Guidelines for Children and Adolescents with Autism.* Bethesda, MD: AOTA Press.

Additional Resources

- Greenspan, S. I., & Wieder, S. (1998). *The child with special needs: Intellectual and emotional growth*. Reading, MA: Addison-Wesley/Longman.
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- Levy, SE, Mandell DS, Schultz, RT (2009). The Lancet. Autism. Published on line Oct. 12, 2009.
- National Autism Center (2009). National Standards Project: Findings and conclusions. http://www.nationalautismcenter.org/affiliates/
- Notbohm, E. (2005). *Ten things every child with autism wishes you knew*. Arlington, TX: Future Horizons.
- Paradiz, V. (2005). *Elijah's cup: A family journey into the community and culture of high-functioning autism and Asperger's syndrome*. Philadelphia: Jessica Kingsley.

Interventions

- The Floortime Foundation: www.floortime.org/
- The Play Project: www.playproject.org/
- Relationship Development Intervention www.rdiconnect.com
- Early Start Denver Model
  Healing Thresholds. *Autism Therapy: Early Start Denver Model (ESDM)*. Retrieved October 28, 2010, from http://autism.healingthresholds.com/therapy/early-start-denver-model-esdm
- TEACCH: www.teacch.com

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Picture Exchange Communication System (PECS) www.pecs.com

Rutter, M., Lecouteur, A., & Lord, C. (2003). Autism Diagnostic Interview–Revised. Los Angeles, Western Psychological Services.

Schaaf, R.C. (2010). Interventions that Address Sensory Dysfunction for Individual's with Autism Spectrum Disorders: Preliminary Evidence for the Superiority of Sensory Integration Compared to Other Sensory Approaches. In Volkmar, F., Cicchetti, D., Reichow, P. Doehring (eds). *Evidence Based Practices in Autism Spectrum Disorders*. Springer.

TEACCH Autism Program. University of North Carolina School of Medicine. www.teacch.com.

Tomchek, SD & Case-Smith, J. (2009) *Occupational therapy practice guidelines for children and adolescents with autism*. Bethesda, MD: AOTA Press.

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For more information, contact the American Occupational Therapy Association, the professional society of occupational therapy, representing 41,000 occupational therapists, occupational therapy assistants, and students working in practice, science, education, and research.

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