ACCESS

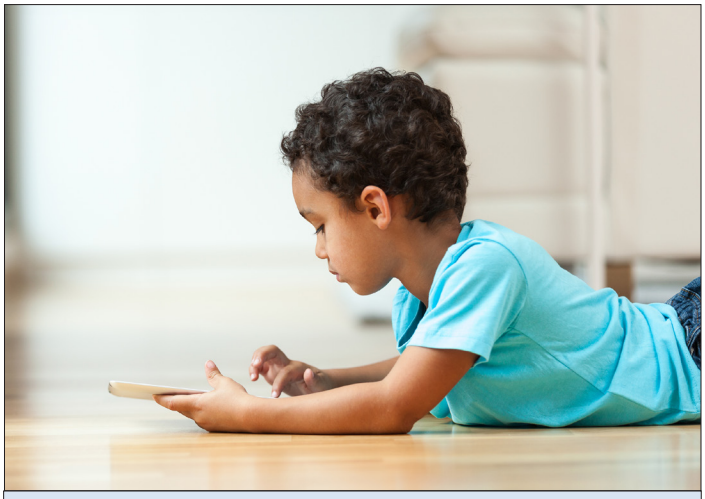
Assuring Comprehensive Care through Enhanced Service Systems for Children with Autism Spectrum Disorder

Summer 2016

Diagnosing and Treating Children with Autism Spectrum Disorder

Challenges in Oregon

- Autism Spectrum Disorder (ASD) is characterized by impairments in reciprocal social relationships, deficits in communication (particularly as used for social interaction), and the presence of restricted and repetitive behaviors and interests.
- ASD now affects about 1:68 children in the United States. (Christensen, D.L. et al., MMWR, 2016) An accurate diagnosis can usually be made by two years of age, and evidence shows that earlier intervention results in better outcomes for children with ASD.
- In Oregon, making a medical diagnosis of ASD and determining eligibility for educational services for ASD are two separate processes. Some children are found eligible for educational services for ASD, but do not receive a medical diagnosis of an ASD from the center-based team, or vice versa. This can create a great deal of confusion for families about whether their child does or does not have an ASD.
- Teams of medical professionals experienced with diagnosing ASD are usually only available at centers in Oregon's major metropolitan areas. The wait list for such an evaluation can be many months long. For children with ASD, this results in lost opportunities to intervene earlier in their development.



The goal of the ACCESS project is to establish a single, valid, and timely ASD identification process in local communities. This process determines both educational eligibility for autism services, and a medical diagnosis for children under the age of five. Timely and accurate ASD diagnosis improves outcomes for children, as well as saving time and money for families and health insurance payers.

- Medical center-based team ASD evaluations are costly to health insurers and to families. Families incur costs due to travel expenses, missed work, and child care for their other children.
- Professionals from metropolitan areas may not be familiar with the services and supports available near the family's home.

Institute on Development & Disability
Oregon Center for Children and Youth with Special Health Needs
503-494-8303 occyshn@ohsu.edu www.occyshn.org
OHSU

How the ACCESS Project Works

The ACCESS project supports eight Autism Spectrum Disorder Identification teams located in communities across Oregon. Medical and educational staff participate together on the teams. Each team includes a pediatrician, a mental health care provider, educational staff (autism specialists, speech pathologists), and a Parent Partner, who is the parent of a child who has ASD.

Educational staff provide their standard educational eligibility evaluation. This includes gathering information about the child's behavior and functioning in various settings.

The pediatrician obtains the child's medical history, completes a family interview based on criteria for ASD from the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, American Psychiatric Association), examines the child, and administers the Screening Test for Autism in Young Children (STAT, Stone et al., 2004, 2008). The STAT is a 20-30 minute structured play observation that allows the physician to make informed behavioral observations.

Mental health care providers participate as regular members on the team or as a consultant as needed. They offer a critical perspective on differential diagnosis (what behaviors may look like ASD, but are actually another disorder).

Parent Partners contact families before the evaluation, attend the team and family conference, and follow up with the family one month after the evaluation. They provide families with peer support, help navigating systems, and local resources.

How the ACCESS Project Helps

children and families:

- Timely, comprehensive evaluation close to home
- Experienced professionals knowledgeable about local resources
- Limited out-of-pocket costs
- One evaluation determines both medical diagnosis and eligibility for educational services

health care providers:

- Timely local evaluation
- Assistance with referral of child and family to local resources
- Assistance with care coordination and family support

educators:

- Early identification of children with ASD and prompt entry to services.
- Advocacy and support for the family from the team's Parent Partner
- Ready access to medical information and consultation

insurers:

- Timely, comprehensive, reliable, and cost-effective evaluation
- Prompt initiation of helpful local services for the child and family

How to Keep Community-Based ASD Teams Working

ACCESS grant funds partially supported the work of ASD teams through August, 2016. Ongoing funding is now needed to support professional education, consultation to teams and team members, coordination of local meetings and reports, and to pay Parent Partners for their work.

The ACCESS project (Assuring Comprehensive Care through Enhanced Service Systems for Children with Autism Spectrum Disorders and other Development Disabilities) is supported by a federal Health Resources & Service Administration grant to the Oregon Center for Children and Youth with Special Health Needs at Oregon Health & Science University (HRSA Grant #H6MMC26249).