



Autism Awareness: Partnership for Change STATE IMPLEMENTATION GRANT SUMMARY Fact Sheet

January 2009

Purpose:

The Children with Special Health Care Needs (CSHCN) Program has been awarded a three year competitive State Implementation Grant for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities from the federal Department of Health and Human Services in the total amount of \$900,000. "Autism Awareness: Partnership for Change" will be funded from September 1, 2008 through August 31, 2011.

Needs:

Autism Spectrum Disorder (ASD) is a complex, lifelong neurodevelopment disability typically appearing during the first three years of life, affecting approximately 8,000 to 12,000 children and youth in Washington State.¹

Early screening, diagnosis, and intervention are essential in order to provide optimal outcomes for children with autism and related developmental disabilities. Many physicians and other health care providers, health insurers, legislators, families, and other important decision-makers who shape the health care system lack a current knowledge of autism, awareness of evidence-based treatment options, and resources available.

According to Autism Task Force (ATF) panelists, this lack of awareness may contribute to physician hesitancy to diagnose; unwillingness on the part of insurers to finance care; and creates a burden for families who must navigate their child's health care and transition to adult life on their own.

Population group to be served:

- 1) Families of children with ASD and developmental disabilities,
- 2) Children and youth with ASD and developmental disabilities,
- 3) Primary care providers, pediatricians, nurses, psychologists, ASD sub-specialists;
- 4) Twenty-one Medical Home Leadership Network teams;
- 5) State agencies, and
- 6) Local community care coordinators and autism related family support organizations.

Background:

The intent of this project is to improve access to quality, comprehensive, coordinated, community-based systems of health care and related services for children and youth with ASD and other developmental disabilities.

Proposed Strategies:

The grant will have three areas of focus, namely:

- ◆ Engage and empower new stakeholders, building on the ATF;
- ◆ Coordinate training to providers and families; and
- ◆ Impact existing benefit systems for children with special health care needs, particularly those with ASD and other developmental disabilities.

Proposed Plan:

Grant activities will build upon 11 ATF recommendations that fall under the DOH scope of work, the Combating Autism Act of 2006, and all six of the CSHCN national performance measures.

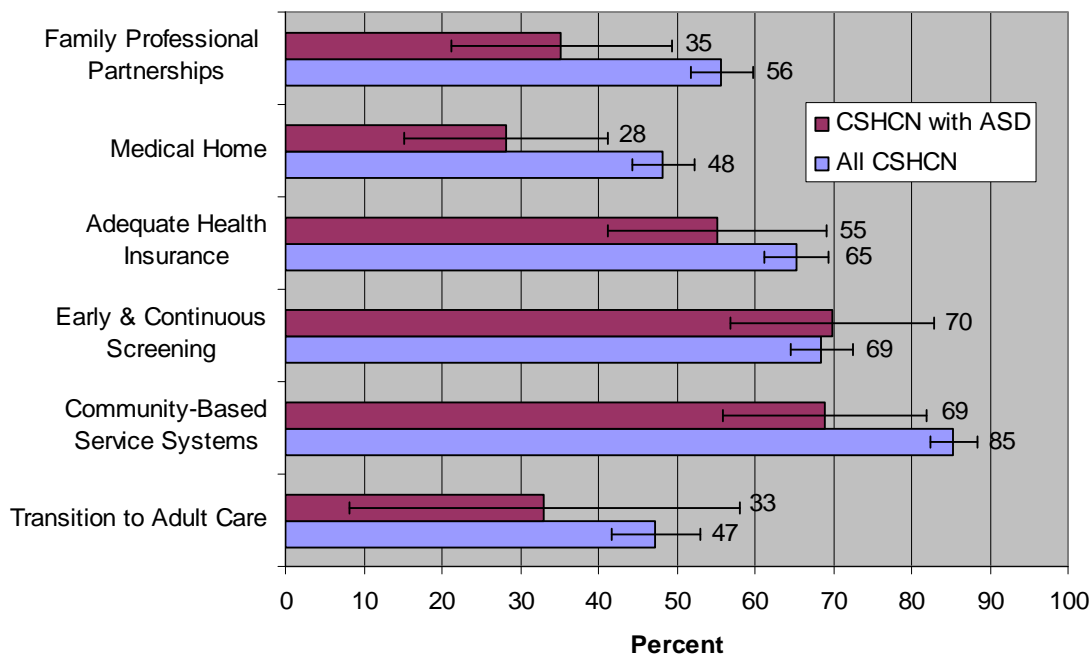
Key Partners & Stakeholders:

- ◆ Leadership Education in Neurodevelopmental Disabilities (LEND)
- ◆ Medical Home Leadership Network, Family Support Organizations
- ◆ Providers—Medical, Psychologists, Care Coordinators, School Nurses
- ◆ All autism organizations, former Autism Task Force Members
- ◆ American Academy of Pediatrics (AAP), Department Social & Health Services (DSHS), Office of Superintendent of Public Instruction (OSPI), Department of Health (DOH), Developmental Disability Council (DDC), Seattle Children's, Legislators, and the Autism Center within the Center of Human Development & Disability at the University of Washington.

Washington State National Performance Measures and Children with ASD:

Based on Washington State data from the National Survey of Children with Special Health Care Needs (NS-CSHCN),² families of children with ASD were significantly less likely to participate in decision-making with their providers and be satisfied with the services they receive, to have a Medical Home, and to find community-based service systems easy to use, compared with all families of children with special health care needs.

National Performance Measures by ASD Status
Washington State, 2005/06 NS-CSHCN



¹The CDC estimates that 1 in 150 8 year old children had ASD in 2007, based on Autism and Developmental Disabilities Monitoring (ADDM) Network. Most states participating in the network had a prevalence range of 5.2 – 7.6 per 1,000 8 year-old children. Washington State estimates were calculated using this range (5.2-7.6/1,000) multiplied by the population of children age 0-18 in Washington in 2008.

²Child and Adolescent Health Measurement Initiative. 2005/06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. Retrieved 1/5/09 from www.cshcndata.org