



# Washington State Medical Home Newsletter

SUMMER 2009

## Issue Focus: Medical Home and Autism

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Autism Spectrum Disorder (ASD) is a complex, lifelong neurodevelopmental disability typically appearing during the first three years of life. It is estimated that approximately 8,000 to 12,000 children and youth in Washington State have some form of autism.

Washington State received two federal grants last year to improve early screening, diagnosis and treatment for children with autism and related developmental disabilities. [Medical Home Leadership Network \(MHLN\) teams](#) are actively participating in improving care through participation in the grants' Combating Autism Advisory Council, state workgroups as well as local activities.

This issue of the WA State Medical Home newsletter shares some of the work being done and opportunities for additional involvement.

## Washington State Combating Autism Grants

In 2005, the Washington State Legislature created the [Caring for Individuals with Autism Task Force](#) to address the growing number of children diagnosed with autism in our state.

During this same timeframe, Congress passed the [National Combating Autism Act of 2006](#), authorizing \$920 million in federal funding over 5 years to fight autism through research, surveillance, awareness and early identification.

The Department of Health's [Children with Special Health Care Needs Program](#) (CSHCN) applied for and was awarded one of only six competitive state grants to help in these efforts. [Autism Awareness: Partnership for Change](#) is a three-year, \$900,000 grant that is focusing on bringing awareness to the importance of early identification and treatment; educating service providers and other professionals on diagnosis and treatment; and improving service systems in Washington State for individuals with autism spectrum disorders and other developmental delays. At the same time the University of Washington's [Leadership Education in Neurodevelopmental and Related Disabilities](#) (LEND) Program applied for and received a LEND "Combating Autism Expansion" training grant. The grants are funded September 2008 through August 2011.

To guide the efforts of the two grants a joint [Combating Autism Advisory Council](#) was formed. This begins the process of carrying out the state's strategic plan to explore and improve needed changes and connect autism-related information, services and research to the public.

As an advisory body, the Council includes previous Autism Task Force members, autism experts, Medical Home Leadership Network team representatives, providers, state agencies, family support organization, legislators, individuals with autism spectrum disorders (ASD) and their families and other leaders. Meeting on a regular basis, the Council aims to: improve

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## First WA State Autism Diagnostic Teams Summit

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The first WA State Autism Diagnostic Teams Summit was held June 4, 2009 in Yakima, WA. The purpose of the meeting was to allow clinical experts from autism centers and clinics serving children and youth across the state to become better acquainted and work toward developing a feasible, comprehensive coordinated state-wide approach for early identification and diagnosis of Autism Spectrum Disorders (ASD) using evidence-based practices.

Earlier in the year, the Washington State Combating Autism Advisory Council's (CAAC) Training and Access Subcommittees identified the need to learn more about best practices for early identification and diagnosis of children with suspected ASDs, as well as which communities were able to provide a multidisciplinary team (MDT) approach to diagnosis.

Based on the enthusiastic interest of MDT clinics across the state, the Northwest Autism Center in Spokane initiated and funded a statewide meeting where MDTs and other regional experts could:

- Get acquainted with other teams and clinics and share information about how each site is currently conducting the diagnostic process.
- Discuss strategies and tools for improving the timeliness and effectiveness of initial identification and diagnostic processes in different regions across the state.
- Establish methods for follow up and continued networking.

The summit was planned in conjunction with the June 5th CAAC meeting. CAAC subcommittee members from the Northwest Autism Center, Children's Village in Yakima, Mary Bridge Children's Hospital, the University of Washington's LEND Program, and the Medical Home Leadership Network Program (through a contract with the Dept of Health CSHCN program) planned the meeting which was generously hosted by the Children's Village.

We appreciate the hard work and dedication of the **MHLN team members** who played a key role in planning and carrying out the summit. Kudos to **Dr. Diane Liebe, Jackie McPhee, and Cindy Carroll** from the Yakima MHLN team and **Dr. Glenn Tripp** from the Pierce County MHLN team who served on the summit planning committee and either gave presentations or led breakout groups at the summit. Kate Orville, Sue Wendel and Dr. Kathy TeKolste, MHLN staff helped facilitate the summit in their roles as either MHLN project staff or LEND staff.

The basic general components of the identification and evaluation process for reaching diagnosis were identified and reflected in a visual pyramid approach (see page 5 of the June 4th [Summit Report](#)). Attendees were encouraged to identify the components in their respective regions needing strengthening to make better use of existing resources and prevent inefficiencies in referral practices. Attendees agreed to work locally with colleagues and relevant community members to address areas of need and to share an update of progress at the next summit meeting (to be planned for next year).

The Summit Report, agenda, participant list, and presentation materials are available online at:

[www.medicalhome.org/leadership/workgroups\\_autismdiag.cfm](http://www.medicalhome.org/leadership/workgroups_autismdiag.cfm)

## Medical Home Teams and Autism Activities

Autism is a focus for a number of MHLN teams including:

**Pierce:** Dr. Glenn Tripp and Brenda Geyers from the MHLN team and Mary Bridge Children's Hospital are active on the CAAC. Their focus this year has been on improved **early identification and diagnosis** for children with ASD by continuing to develop ASD diagnostic and treatment program at Mary Bridge Children's Hospital; collaborate with state Combating Autism Advisory Council to improve diagnosis and treatment in WA; and develop and produce prototype "Tiers to ASD Diagnosis" pyramid model.

**Lewis:** Dr. Pope from Pope's Kids Place is on the CAAC and interested in developing **Autism programs for his clinics and county**. He recently received a CATCH planning grant for an **Autism Learning Center**. NW Pediatric Center and Parent to Parent MHLN team members are also involved in improving ASD services locally.

**Yakima:** The team is focusing on early **identification, diagnostic and intervention programs** for children with ASD in Yakima and the state and very involved in the CAAC.

**Walla Walla:** The focus for their 2009-10 activities is exploring options for **bringing an ASD Diagnostic team** to Walla Walla that can provide multidisciplinary services and assist in developing care plans.

**Skagit:** Cindy Hubert has participated in CAAC activities and is exploring ideas with community colleagues including:

- \* **ADOS training** (including funding) for birth to three providers.
- \* **"Luncheon Learns"** – Autism themed "Grand Rounds" type of event(s) at Skagit Valley Hospital focused toward the needs of family practice MDs and pediatricians. Professional(s) would need to be identified (and funded) to speak; structure already in place to organize and advertise the event.
- \* **Regional MDT specific to Autism** that could act as a pre-screening entity for children that would otherwise be immediately referred to UW and Seattle Children's. Long term goal would be more professionals closer to home who are able to provide the services families need in a shorter time frame and within the parameters of their insurance coverage. Dream would be to have the participation of a developmental pediatrician and/or child psychiatrist (or clinical psychologist) on the regional team and be able to provide follow-up as needed.
- \* Regional and or local **Autism task force group** meeting to assess needs and plan strategies to address the needs.

## New Listserv: Focused Clinical Discussion on Medical Issues in Autism

Clinicians at the June 4th Autism Diagnostic Teams Summit requested ongoing focused discussion on clinical issues related to autism spectrum disorders. Dr. Charles "Chuck" Cowan, Medical Director of the Seattle Children's Autism Center (and former long-time King County MHLN team member) graciously offered to take the lead and is moderating a listserv to address these issues. The Medautism listserv is up and running with 58 members. Postings to date have included what clinicians are doing to provide a workup for "regressive" autism as well as issues related to children with asperger's and kleptomania. Other topics Dr. Cowan anticipates discussing include continuing a discussion about the genetic work up of these children as well as discussions of: 1. EEGs, 2. MRIs, 3. Metabolic workup, 4. Sleep studies, 5. GI workup, and 6. DAN therapies.

If you are interested in participating in the listserv, please contact Dr. Cowan at: Charles.Cowan@seattlechildrens.org or go to <https://mailman1.u.washington.edu/mailman/listinfo/medautism>. (Tip: If you do not have a UW email address, and want to access the listserv archives, please save the password that will be automatically sent to you by the system when your request is accepted.)

### *WA Combating Autism Grants- Continued from page 1....*

autism awareness; support research on evidence-based treatment and care; impact existing benefit and care systems for children and youth with special health care needs; and work toward assuring that children and youth with autism receive early and appropriate identification, diagnosis, and intervention.

The Council has formed subcommittees which take up various tracks of work as they relate to the grants. These subcommittees include: Family Involvement, Public Policy, Access and Training.

## The Washington State Medical Home Project



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Children with Special Health Care Needs Program  
[www.doh.wa.gov/cfh/mch/cshchome2.htm](http://www.doh.wa.gov/cfh/mch/cshchome2.htm)

### Survey Results from Autism Diagnostic Teams Available

Surveys completed by centers using a multidisciplinary team (MDT) approach to diagnosing Autism Spectrum Disorders and related disabilities with children in Washington State are now available.

The surveys describe how ASD diagnostic services are provided in MDT clinics and centers. Topics include contact information, clinic schedule and capacity, and personnel (disciplines represented, bilingual capacity). Respondents detailed their intake process, how they provide diagnostic evaluations and share results with families and primary care providers, and what follow-up they provide. They also addressed how many children referred for an ASD evaluation ended up with other diagnoses and what those typically were. Finally, respondents shared information on how they were funded and the key challenges faced by their multidisciplinary diagnostic team.

The survey project came from discussion at the Combating Autism Advisory Council's Training Subcommittee. The initial planning group for the MDT surveys included representatives from: UW CHDD (LEND/Child Development Clinic and MHLN project), Northwest Autism Center, Yakima Children's Village, UW Autism Center and the CADET program.

The following Clinics/Centers completed surveys:

- \* [ASTAR](#)- Autism Spectrum Treatment and Research Center (Seattle)
- \* [CADET](#) - Comprehensive Autistic Disorders Evaluation Team (Tri-Cities)
- \* [Children's Village](#) (Yakima)
- \* [Legacy Emanuel Children's Hospital](#) (Vancouver)
- \* [Madigan Army Medical Center- Autism Spectrum Disorders Clinic](#) (Tacoma)
- \* [Mary Bridge Children's Hospital and Health Center](#) (Tacoma)
- \* [Seattle Children's Autism Center](#) (Seattle)
- \* [University of Washington- Autism Clinic](#) (Seattle and Tacoma)
- \* [University of Washington- Center on Human Development and Disability Child Development Clinic](#) (Seattle)

Survey results are available at: [www.medicalhome.org/leadership/workgroups\\_autismdiag.cfm](http://www.medicalhome.org/leadership/workgroups_autismdiag.cfm) . Clinics who have not yet participated but would like to are welcome. Information is on the above webpage.