

# Washington State Medical Home E-Update

News from the Washington State Medical Home Partnerships Project

## Spring 2014

## The Community Asset Mapping (CAM) Project is Now Four Years Old!

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KEY

CAM
communities with
a Universal
Developmental
Screening Focus

communities with an Autism Focus

## Overview

Since the first facilitated meeting in Walla Walla in February 2010, nine communities across Washington have improved early identification and diagnosis of children with autism and other developmental concerns by bringing together pediatricians, families, educators, public health, early intervention, and other service providers in their communities. Through relationships developed across silos, communities have expanded existing services and identified new resources, improved collaborations and unlocked new energy.

The first CAM communities focused on children with or at risk for Autism Spectrum Disorders (ASD). Through the federal Great MINDS (Medical Homes Include Developmental Screening) grant (2011-14), Clark, Spokane and now Snohomish have expanded the focus to all young children.

In April 2014, the Medical Home Partnerships Project gathered key stakeholders from each of the participating communities, the WA Department of Health, the University of Washington <u>LEND</u> (Leadership Education in Neurodevelopmental and Related Disabilities), parent organizations, and parents for an in-person meeting. It was a day of celebrating our successes, networking, and collaborating on challenges the communities face in their work to date and as they move forward. Thank you to the DOH Great MINDs grant for providing travel funds for participants!

Each of the communities shared written <u>highlights</u> from their activities prior to the stakeholders' meeting. This newsletter includes additional information shared at the April meeting. We continue to work on ways to connect communities to the work being done around our state, and welcome your input as we carry on this work.

It is a privilege to be part of this project and network of communities who are doing amazing work with very little funding. The passion and commitment from each person is humbling and fuels our own strength to continue to advocate for services for our own children as well as all children, adolescents, and adults with developmental disabilities.

--Amy Carlsen, RN, Kate Orville, MPH and Kathy TeKolste, MD

The CAM process involves bringing key stakeholders together to identify:

- how information about typical child development and developmental "red flags" or concerns is shared in the community
- who is doing standardized developmental screening to identify concerns early
- who is doing more focused screenings
- what is available, and where, for children who need a more in-depth assessment.

As a community, the assembled group identifies gaps and opportunities and chooses two priorities to address as an ongoing coalition.

For more information go to: Community Asset Mapping



Click here to see Pyramid

## CAM Communities with a Universal Developmental Screening Focus for All Children

Universal Developmental Screening means universal in two ways-

- 1) All children are screened for developmental concerns
- 2) There is "no wrong door" to screening. Children may receive screening in their Primary Care Provider's office, at Head Start, at the local Early Intervention Program, through WithinReach's HelpMeGrow, and others. The community works together to figure out how to ensure that results are shared, with family permission, across providers to prevent under or over screening.

Below are overviews of each CAM community that has Universal Developmental Screening as a focus:

**Benton-Franklin** held their first community-wide meeting focusing on autism in February 2011. They are currently in the process of restructuring their group to start a new effort that combines Universal Developmental Screening (UDS) efforts and Medical Home team outreach.

Benton-Franklin recently surveyed primary care providers and childcare providers to determine their use of developmental screening tools and their need for further training.

- Child Care Provider Trainings: Based on the survey responses, trainings for childcare providers are in development and will be completed with the help of partners from the Benton Franklin Early Learning Alliance. STARS credits are issued for a class on <a href="Adverse Childhood Experience Study">Adverse Childhood Experience Study</a> (ACEs) in April and a class on UDS is planned for late summer. The community offers 6-9 STARS classes a year.
- Physician trainings: Educational trainings for physicians started on May 29, 2014 through outreach efforts of the Washington Chapter of the American Academy of Pediatrics (WCAAP) under the WA Department of Health's Great MINDS (Medical Homes Include Developmental Screening) grant. Several clinics in the regions will receive information that includes:
  - o explaining the referral process and distributing the referral map with the process outlined,
  - o explaining the timelines for evaluation after screening (45 days),
  - o highlighting early intervention activities that can be started while parents are waiting for a formal diagnosis,
  - o distributing <u>CDC 'Learn the Signs Act Early' materials</u> to providers with information on how to obtain these materials for their office and promoting an activities sheet along with the ASQ as teaching moments for typical child development.

*Clark County* held their first community-wide meeting focusing on UDS in June 2013. Clark County has many resources for children in need of Early Intervention (EI), including three EI provider sites within the Vancouver area and surrounding towns. In addition, the WA State School for the Blind and School for the Deaf are located in Vancouver. Clark College's Early Learning Center contracts with Early Support for Infants and Toddlers (ESIT) to provide therapy to eligible children. Families can get college credit if they bring their child into the early childhood classroom at the Early Learning Center to receive therapy.

The Clark County CAM Workgroup has produced a <u>Roadmap to Clark County Community Services</u> and a resource flipbook guide for CSHCN (Children with Special Health Care Needs) and their families. The roadmap, flip-guide and CDC's brochure, "Track Your Child's Developmental Milestones" are being distributed to childcare settings, WIC, food banks, primary care medical offices and other clinical settings.

**Spokane County** held their first community-wide meeting focusing on UDS in June 2013. Prior to that meeting there was a focus on improving access to Early Intervention services in the Spokane region by increasing the use of standardized developmental screening tools. These efforts focused on Child Find and primary care providers. Because of these efforts, there has been an increase in referrals to the Infant Toddler Network resulting in an increase in the number of children with active Individual Family Service Plans (IFSP) in Spokane.

The Spokane regional Health Jurisdiction received a Providence Health Care Grant to support works done by the Infant Toddler Network and to support the work of Heather Wallace, a Public Health Educator in the Spokane Health Jurisdiction office. Heather's work involves distributing materials highlighting the importance of

developmental screenings for young children, as well as training on developmental milestones to childcare providers, primary care providers, WIC, and parents. The web-based information for the <a href="Spokane Health District">Spokane Health District</a> Infant Toddler Network and Health District's <a href="CSHCN">CSHCN</a> site have been updated. The Workgroup is collaborating with the Northwest Autism Center to provide screening for autism and access to Applied Behavioral Analysis (ABA) therapy services for children who qualify.

**Snohomish County** is getting ready for their first facilitated community meeting with approximately 35 key stakeholders on June 23, 2014. They are focusing on finding all children 0-6 years old in Snohomish County and on Camano Island with developmental delays as early as possible. ChildStrive (formerly the Little Red Schoolhouse), a large Early Intervention center in Snohomish, is leading these efforts with an active Steering Committee that has been meeting monthly since February to prepare. The workgroup developed surveys for parents and for community providers (medical, childcare, schools, early intervention etc) to find out who is doing what type of developmental screening and what the barriers might be to screening all children. As of May 23<sup>rd</sup>, they had received 104 responses to the Community Partner survey and 49 to the parent survey. Results will be shared at the June 23<sup>rd</sup> meeting.

**Yakima** is the home base of the Central Washington Universal Developmental Screening (UDS) Workgroup. This project is funded by local grants including Yakima Community Foundation, Project LAUNCH-Yakima, South Central Infant Toddler Consultation Project, and Childcare Aware through Catholic Family Services, Investing in Children Coalition.

In 2011-2012, there were 3 local medical practices implementing standardized developmental screening tools. Since the 2012 evaluation, 16 additional clinics became partners for developmental screening implementation, and 135 staff have been trained. Currently 1 clinic has not moved forward, 5 are in the planning stages, 5 are in partial implementation stages and 7 are fully implementing formal developmental screening. Additionally, two federally qualified health clinics have targeted UDS as a priority and have developed pilot programs within their own clinic system to be implemented corporate wide. Not only does this affect clinics within the Yakima Valley from Naches to Grandview, but this also affects clinics from Ellensburg and Prosser to Walla Walla and Spokane. The goal embedded within those clinic systems is to assure that every child is screened. Although we do not have exact data counts for these clinics, the predicted scope is extensive.

Eight childcare facilities, including two home-based centers, participated in a Child Care UDS Pilot Project. Seventy-two (72) staff members were trained. Fifty-four (54) parents also participated in family nights that provided general information about child development, milestones, and the importance of standardized developmental screening, highlighting parent-completed screening tools. Childcare programs are beginning some implementation of developmental screening. From October 2013 through February 2014, 58 developmental screenings were completed in these 8 centers. An additional 110 screens were distributed to parents. To date, four (4) of the 58 (6.8%) children have been referred to community health and/or early intervention providers for further developmental evaluation, follow-up and supports.

The Central Washington UDS workgroup meets on a monthly basis for 1.5 hrs with members from a variety of local, regional, and state partnerships, with only rare interruption due to the end of local grant funding. Due to their prior outreach to primary care providers, members of this Central Washington UDS workgroup are collaborating, with outreach efforts of the WCAAP under the Great MINDS (Medical Homes Include Developmental Screening) grant, to provide regional medical trainings and learning collaborative for UDS. These trainings started this spring in the Walla Walla and Tri Cities regions.

## **CAM Communities with an Autism Focus**

*Island County* held their first community-wide meeting focusing on autism diagnosis and services in August 2010.

The Island County Autism Taskforce meets quarterly and includes parents, physicians, mental health providers, Early Intervention providers, representatives from school districts, and ABA providers. They have support from the County Developmental Disabilities program to facilitate their meetings and recently got funding for administrative support to help prepare for the Taskforce meetings. The Island County Autism Taskforce is a subcommittee of the local Interagency Coordinating Council (ICC).

The Island County Taskforce has developed a Memorandum of Understanding between Birth to 3 providers, ABA providers, and families. This Memorandum of Understanding provides a description of how Toddler Learning Center and Island County ABA providers will collaborate with one another to provide services for children in Island County who are on an Individualized Family Service Plan (IFSP). The WA State Department of Early Learning "Guidelines for Providing IDEA, Part C Services for Toddlers With, At Risk for, or Who Are Suspected to have Autism Spectrum Disorder (ASD) in Washington State" were used to help inform this Memorandum of Understanding.

Lewis County held their first community-wide meeting focusing on autism diagnosis and services in February 2010. To improve autism diagnosis, they developed a School Medical Autism Review Team (SMART) which consists of Early Intervention providers, a pediatrician, a school psychologist, special education directors, a Behavioral Analyst, and occupational and physical therapists. Members of the SMART team meet every other week to discuss children who might need more assessment or intervention. The goal is to get kids from Lewis County to be able to receive a diagnosis of autism locally. Because of the efforts of the SMART Team, Lewis County recently hosted an outreach assessment 'clinic' with Glenn Tripp, MD and Mary Chmelik, ARNP, from Mary Bridge Hospital in Tacoma. Dr Tripp and Mary assessed 9 children for a possible autism diagnosis.

Programs focusing on improving services for children and families initiated by the Lewis County Autism Coalition include:

- Day camp for 9-14 year olds who have autism, as well as typical peers
- A similar weekly summer camp for ages 3-8
- An annual conference, scheduled for October 2014
- A Behavioral Treatment program housed at Pope's Kids Place
- The <u>LCAC website</u>.

**Skagit County** held their first community-wide meeting focusing on autism diagnosis and services in May 2012. The Skagit County Autism Partnership grew out of the local ICC and is now a smaller workgroup of the ICC. Their focus is on improving the school-medical provider connection in hopes of improving the momentum for stronger community-based diagnostics, treatment, and resources.

The community has been energized through collaboration with Wendy Stone, PhD. and director of the <a href="UW READi">UW READi</a>
<a href="Lab">Lab</a>
Through funding from Dr. Stone's <a href="ASAP! Grant">ASAP! Grant</a>
, local medical and early childhood providers have been trained on improving diagnosis in young children with the use of the Screening Tool for Autism in Toddlers (STAT). In addition, early childhood providers and parents have received training in an early intervention technique to assist young children with autism called Reciprocal Imitation Training (RIT).

**Walla Walla** is continuing their CAM work which began in February 2010. Improving autism diagnostic and treatment services for Walla Walla County children continues to be one of the primary activities the Walla Walla Medical Home Leadership Network Team has chosen to include in their Team Action Plan.

A workgroup comprised of members of the Medical Home Leadership Network Team meet monthly to work on the formation of a Walla Walla Autism and Other Neurodevelopmental Disorders Diagnostic Team. The workgroup is currently exploring the feasibility of the Walla Walla Public Schools Speech and Language therapists being diagnostic team members. Linda Ivy, PhD, Licensed Clinical Psychologist, and Joseph Wren, M.D., Walla Walla Pediatrician are committed to being members of the team. Dr. Ivy did her clinical internship through the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program at the Child Development and Rehabilitation Center at Oregon Health and Science University. Her training included rotations in the Early Childhood Assessment Team, the Child Development Assessment Clinic, and the Autism Diagnostic Clinic, as well as other clinics such as pediatric pain, behavioral pediatrics, and neurobehavioral assessment.

Other tasks of the Autism Diagnostic Team workgroup include researching a location for the diagnostic team to see children, credentialing of team members if required by the clinic or hospital hosting the diagnostic team,

scheduling, billing and insurance issues, exploring becoming a Health Care Authority-designated Center of Excellence, and the establishment of ABA therapy services for Walla Walla County children. Dr. Ivy and Valerie Remboldt, R.N., B.S.N., M.P.H., Walla Walla County Health Department Children with Special Health Care Needs Coordinator met with Beth Ellen Davis M.D., M.P.H. Director of the University of Washington Clinical Training Unit and UW LEND program, and Katherine TeKolste M.D., Co-Director of the Medical Home Partnerships Project to discuss training and consulting for diagnostic team members and other Walla Walla professionals.

The Autism and Other Neurodevelopmental Disorders Diagnostic Team workgroup members are also all members of the Walla Walla Children's Center Visioning Group. If the dream of establishing a Center for Children with Special Health Care Needs becomes a reality, the hope is that the Autism and Other Neurodevelopmental Disorders Diagnostic Team would be based there.

**Yakima's** Autism Oversight Committee (AOC) started meeting in 2005. Parents are actively involved in the AOC work. Some of their contributions include working to decrease duplication, maximize resources and improve services for children with autism, from Birth through 18 years old, and their families. Initial participants included school district personnel, Educational Service Districts staff, and medical professionals who met to discuss overall services for children with autism. The committee has expanded to include mental health agencies working to offer ABA services in Yakima County. They are currently in the process of mapping mental and behavioral health services in the Yakima community to find out which insurances they take and outline each program's strengths and gaps.

## **Challenges of CAM Communities**

During our CAM Stakeholder meeting, we took time to identify and try to address a few of the challenges communities are facing. The intent was to brainstorm together from the varied experiences and knowledge of the greater network of communities.

Below is a summary of 3 challenges we discussed:

1. How do you reach physicians to provide training on Universal Developmental Screening (UDS)?

Communities are eager to provide training on UDS to both pediatricians and family medicine doctors. The challenge is



Participants from left to right Bill Cheney, Amy Carlsen, Susan Ray, Cindy Carroll, Susan Atkins, and Wendy Stone.

finding a time that works for the physicians. Members suggested trying to meet with the doctors at 7am. Other communities have sent surveys to physicians to try to target their interest in developmental screening. These surveys were sent to physicians via different methods including email and sending the survey directly to the office clinic managers. Communities have found that physicians are sometimes reluctant to screen because they are not knowledgeable about resources for next steps once a screen demonstrates concern. Suggestions included distributing community road maps to services, helping physicians and families better understand the referral process, and working on improving the collaboration between schools and medical providers in the community.

- 2. How do you put a Roadmap together and distribute it with little or no funding?
  - Communities are very creative at using a variety of resources to create Roadmaps for services in their community both for parents and providers. Some ideas include a nurse or public health intern developing the roadmap and getting small grants or using in-kind services to print materials. Some communities have chosen not to create an official roadmap document, but use the resource guide from the United Way or connect to the resource database at <a href="Parenthelp123">Parenthelp123</a>. In some communities the ICC or Parent 2 Parent programs maintain an updated resource list. In Walla Walla, the <a href="Eastern WA ASD Association">Eastern WA ASD Association</a> distributes boxes with a collection of resource for families who have children waiting for a diagnostic assessment or are newly diagnosed with autism.
- 3. What do you do when folks in the community won't talk with each other either for political or other reasons?

Some communities opt for a 'cooling off period' when this occurs. Other ideas included hiring a professional facilitator from the outside and bringing the parties together under another common interest. It is always a good idea to have yearly 'check-ins' within each coalition to 1) make sure that the group continues to agree on, and is meeting, its stated objectives and 2) recommit to the mission and core values of the workgroup.

## **Future Opportunities**

The final part of the CAM Stakeholder meeting day was spent on future opportunities for communities to continue and enhance their great work. A lot of the discussion was around training opportunities for parents, childcare providers and medical providers.

- 1. Training opportunities available for parents include:
  - Training on general developmental awareness through public outreach, including the LTSAE materials and the newly developed 'Birth to 5: Watch Me Thrive!' initiative from the US Depts. of Education and Health & Human Services.
  - RIT training/ opportunities for training through grant opportunities; see the information on the <u>UW</u> READi Lab.
  - Parent leadership training through the Medical Home Partnership Project; contact Amy Carlsen at carlsa@uw.edu for more information.
  - Distance learning through the <u>Autism 100</u> and <u>Autism 200</u> series
  - On-line training modules/podcasts
  - Text4baby and other apps
- 2. Training opportunities for childcare providers can be made available in the local community, for instance:
  - STARS credits offered for childcare providers for training on autism and developmental screening at community colleges Spokane and Lewis County
  - RIT training/opportunities for training through grant opportunities. See information on the <u>UW READI Lab.</u>
  - Classes are offered at the Early Childhood Conferences in Tacoma and Spokane
- 3. Training opportunities for primary care providers are available on how to do developmental screening in the practice and referral to services in local communities through the Great MINDS Project at. WCAAP. For more information, contact Samantha Wolfe at <a href="mailto:swolfe@wcaap.org">swolfe@wcaap.org</a>. If a medical practice or other community service provider is interested in becoming an Autism Diagnostic Center of Excellence (COE), support is available through the WA State Health Care Authority. Contact Gail Kreiger at 360-725-1681 for more information.

Other opportunities discussed were the possibility for communities to link with the ACEs work at their local public health department and exploring possible data system connections to support communities in providing coordinated care for their families through medical home resources.

## **Resources**

## Birth to 5: Watch Me Thrive!

Launch of the federal multi-agency initiative, Birth to 5: Watch Me Thrive! brings attention and resources to early detection of children at risk for adverse developmental and behavioral outcomes.

Visit Watch Me Thrive for more information

## **Northwest Bulletin:**

The <u>spring 2014 issue</u> of the *Northwest Bulletin* focuses on developmental screening for young children, including resources for Washington state. It is the first of a two-part series: the fall issue will focus on developmental screening for school-aged children and adolescents.

Autism 200 Series: Panel Discussion – Developing and Advocating for Services in Local Communities

Thursday, November 21, 20137 to 8:30 p.m. in Wright Auditorium at Seattle Children's Hospital

http://www.youtube.com/watch?v=11ldGCDjpf8&feature=youtu.be Bill Cheney (Skagit County), Rene Denman (Island County), Amy Carlsen (facilitator), and Cindy Carroll (Yakima) shared their

personal stories and insights on the successes and challenges of creating CAM networks in their communities and offer inspiration on how others may be able to improve diagnosis and services for children with autism and their families in your community.



Panelists from left to right Bill Cheney, Rene Denman, Amy Carlsen, and Cindy Carroll.

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MHLN Community Teams: <a href="www.medicalhome.org/leadership/teams.cfm">www.medicalhome.org/leadership/teams.cfm</a>

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