

# **Community Asset Mapping Project Benton and Franklin Communities February 11, 2011**

## **Description of Project:**

The goal of the Community Asset Mapping Project is to establish coordinated and accessible systems for families, medical providers, schools and other service providers to ensure timely screening and assessment, a reliable diagnosis, and evidence-based services in their community for autism spectrum disorders (ASDs) and other developmental concerns.

The Community Asset Mapping Project is a pilot project of the Washington State Combating Autism Advisory Council (CAAC). It was envisioned at the June 2009 Autism Multidisciplinary Diagnostic Summit as a way to help communities organize themselves to support effective identification and diagnosis of ASDs and other developmental concerns and significantly reduce wait times for families at diagnostic centers.

At the invitation of local champions, a technical assistance (TA) team from the CAAC assists interested communities in identifying key representatives from families and service providers who care for children with autism and related disabilities. These community stakeholders are invited to a half-day facilitated meeting where they identify how developmental awareness, general developmental screening, focused screening, general assessment and evaluation occur for children in the community-who does what, where are the strengths and the gaps. Participants prioritize gaps and begin planning for next steps to address at least two of the gaps. The CAAC TA team assists the Community Asset Mapping coalition as they begin their work, linking them with other communities doing similar work as well as other resources.

## **Geographic Area:**

The geographic area for the purposes of the local Community Asset Mapping (CAM) coalition is Benton and Franklin counties in Washington State. Service providers in Benton and Franklin Counties also serve some children from Adams County, Walla Walla, and Oregon.

## **Participants:**

Local champions who helped begin this process included Carla Prock RN, Children with Special Health Care Needs Coordinator, Benton-Franklin Health Department and BF Medical Home Leadership Network team coordinator, Christine Lindgren, Director, Responding to Autism Center and Melissa Brooks, RN, parent and Parent Resource Coordinator RAC. Dr. Scott Grewe, Director of CADET, attended the first

Autism Multidisciplinary Diagnostic Team summit and initially suggested Benton-Franklin as a CAM pilot site. The United Way of Benton and Franklin Counties provided the meeting space for the day.

A total of 18 people from Benton and Franklin counties attended the meeting on February 11, 2011. These included representatives from the Division of Developmental Disabilities, Public Health and Children with Special Healthcare Needs Nurses, Parents, Private Counselors, a pediatrician, Responding to Autism Center, Kadlec Neurologic Center, the Autism Society of WA, Richland and Pasco school districts, WA PAVE, the ARC of Tri-Cities, and Children's Developmental Center (which also represented CADET as Dr. Grewe was unable to attend due to a scheduling conflict. Dr. Grewe sent in notes on recent activities at CADET in advance of the meeting. Please see notes in Appendix).

**Individuals/Groups unable to attend:**

The following groups were felt to be missing from the meeting and will be invited to participate in ongoing activities: Head Start, Early Head Start, School psychologists, additional Pediatric Clinics, Community Health Clinics and CPS, Dr. Scott Grewe and other clinicians from the diagnostic center CADET.

## The following summarizes the Community Asset Mapping process in Benton-Franklin Counties

### Step One: Identifying our community assets

The Tiers to Autism Spectrum Disorders Pyramid was used as a template to identify current activities and systems within the community. Each of the pyramid tiers was defined and the community participated in a full group discussion of activities occurring at that level. (See full pyramid and examples at each level in Appendices)

Level of Pyramid	Definition of Level	Community Assets	Activities
<b>Child Development Awareness</b>	Promote parent, provider, and community awareness of typical child development.	<ul style="list-style-type: none"> <li>• Parent to Parent</li> <li>• Family Resource Coordinators</li> <li>• Public Service Announcements</li> <li>• “Our Babies Can’t Wait”</li> <li>• Head Start/ ECEAP</li> <li>• Child Find B-21</li> <li>• WIC</li> <li>• DD Intake</li> <li>• Kadlec Resource Center</li> <li>• Child Development Center</li> <li>• Columbia Basin College parent co-ops</li> <li>• Responding to Autism Center</li> <li>• Ready for Kindergarten</li> <li>• Kadlec physicians office</li> <li>• Child Profile Mailings</li> </ul>	<ul style="list-style-type: none"> <li>• Monthly trainings on topics chosen by parents</li> <li>• Bulletin board, general developmental awareness</li> <li>• United Way Program, TEXT4BABIES</li> <li>• Basic education to parents</li> <li>• Gives additional information and referral to MD/PHN</li> <li>• Resource library open to the public</li> <li>• Trainings to daycare providers</li> <li>• Community trainings, Autism 101, other autism trainings, Responding to Autism Event</li> <li>• Look at Me Brochure</li> <li>• Educate parents and other providers regarding resources for assessment</li> </ul>

Level of Pyramid	Definition of Level	Community Assets	Activities
		<ul style="list-style-type: none"> <li>• Mental Health Child case Managers</li> <li>• LaLeche League</li> <li>• Tri-Tech parenting classes</li> <li>• MOPS, church groups</li> <li>• Pediatrician offices</li> </ul>	
<b>General Developmental Screening</b>	Routine surveillance and screening within well-child visits following AAP guidelines of 9, 18, 24, and 30 months.	<ul style="list-style-type: none"> <li>• Kadlec Regional Medical Center</li> <li>• Kadlec daycare</li> <li>• Talking to Parents training for childcare providers (ICC project)</li> <li>• Head Start/ECEAP</li> <li>• Child Find</li> <li>• Public health nurses</li> <li>• Family Resources coordinators</li> <li>• Well child checks</li> <li>• WA PAVE</li> </ul>	<ul style="list-style-type: none"> <li>• NICU follow up clinic</li> <li>• Speech therapy screenings</li> <li>• Learned about ASQ, how to talk to parents when you refer children</li>   <li>• Use ASQ</li> <li>• Use ASQ, 6.5FTE total</li>   <li>• Can be accessed at any level for parent support</li> </ul>
<b>Focused Developmental Screening</b>	Targeted developmental screening using validated tools to identify children needing further evaluation for specific developmental concerns.	<ul style="list-style-type: none"> <li>• Responding to Autism Center</li>   <li>• Schools</li> <li>• Head Start/Early Head Start</li> <li>• Public Health Nurses</li> <li>• Some pediatricians are trained in MCHAT, ASQ-SE</li> <li>• Kadlec</li> </ul>	<ul style="list-style-type: none"> <li>• Screenings twice a month, use MCHAT, GARS II or CARS, Social Emotional Questionnaire</li> <li>• Use CARS</li>   <li>• Use ASQSE, MCHAT</li>   <li>• Free speech screenings</li> </ul>
<b>General Developmental Assessment</b>	General developmental assessment by providers with specific training using	<ul style="list-style-type: none"> <li>• Public Schools: assessment team and developmental preschool personnel</li> </ul>	<ul style="list-style-type: none"> <li>• Cognitive-academic, social, language, motor, adaptive</li> </ul>

Level of Pyramid	Definition of Level	Community Assets	Activities
	validated tools to provide a differential diagnosis for developmental delay	<ul style="list-style-type: none"> <li>• Kadlec formal assessment</li> <li>• Children’s Developmental Center</li> </ul>	<ul style="list-style-type: none"> <li>• PT,OT, SLP</li> </ul>
<b>Autism Spectrum Evaluation and Diagnosis</b>	In-depth functional assessment for autism by clinicians with specific training and experience using validated tools to make an ASD diagnosis	<ul style="list-style-type: none"> <li>• CADET</li> <li>• Seattle Children’s Autism clinic</li> <li>• CHDD/UW Autism Clinic</li> </ul>	<ul style="list-style-type: none"> <li>• Dr Scott Grewe clinical psychologist, SLP, motor therapist, Early intervention specialist</li> </ul>

<b><u>Key to developmental screening tool acronyms:</u></b>	
ASQ - Ages and Stages Questionnaire	DECA - Devereaux Early Childhood Assessment
DAYC- Developmental Assessment of Young Children	ESI – Early Screening Inventory
ESPG	
CARS- Childhood Autism Rating Scale	GARS- Gilliam Autism Rating Scale
MCHAT-Modified Checklist for Autism in Toddlers	

## Step Two: Identifying Areas for Improvement in Our Community

The areas for improvement in the community were then identified using a full group facilitated discussion. After the areas were identified, each community member present was given 2 red dots to use to vote for their top 2 priorities. These following were the areas identified and the number of votes each area received.

1. What's the next step when child care providers have concerns about a child? Providers need help in applying modifications so that the child doesn't get kicked out of the facility.
2. Underserved groups in the community are:
  - a. Hispanics
  - b. Homeschooled children
  - c. Stay at home moms
3. Only some doctors use standardized developmental screens (4 votes)
  - a. Many doctors have a 'wait and see' attitude.
  - b. Many families do not see PCPs who do developmental screening
  - c. Families don't understand the medical home concept
4. School psychologists hesitant to say child has ASD
  - a. If disagree with diagnosis from CADET, unsure where to go
5. Difficulty getting medical diagnosis for children with Medicaid or some other health insurances (3 votes)
  - a. For families on Medicaid there is a \$250 fee to get services at CADET. CADET is in the process of trying to build up a scholarship fund for these families
6. No access to neurodevelopmental pediatricians (6 votes)
  - a. No neurological outreach clinics (2 votes)
  - b. Only Responding to Autism does regular ASD focused screenings
  - c. For children older than 10, only access to Dr. Grewe as individual psychologist (1 vote)
  - d. Several other psychologists in the area diagnose ASD but not as known (and may not have as much knowledge/experience about ASD diagnosis)
  - e. Also: gap for new migrant kids who are older
7. Older kids aren't getting recognized in schools
  - a. Getting past gatekeepers into services (good once in services)
  - b. Older kids may have misdiagnosis
8. Difficulty navigating systems (for everyone)- Hard for parents to figure out services (10 votes)
  - a. Need for maps of local community resources for families and for providers
  - b. Parents not on Medicaid don't get transportation support

### Highest Priority Gaps:

1. System is unclear for providers and families- need for navigating systems road map(s) (10 votes)
2. Lack of neurological services/outreach clinics / neurodevelopmental pediatricians. (8 votes)
3. Lack of standardized developmental screening (4 votes)
4. Insurance Issues for ASD diagnosis (4 votes)
5. Availability of diagnostic services for kids 10+ (1 vote)

### Step Three: Identification of our Community Priorities. A Starting Place

Priority	Lead People	Next Steps & Timeline
1. Develop a "Road Map" to services for providers & families specific to Benton and Franklin counties	Carla Prock Kristy Wessels	Amy will send the community examples of roadmaps being developed in other places throughout WA by the middle of March, 2011
2. Recruit a neurodevelopmental pediatrician for the community	Carla Prock	Carla will send a letter on behalf of the community asset mapping group and the CSHCN to the 3 hospitals and CEOs
3. Identify regular training venues	Carla Prock	Community members will send lists of training opportunities, ie Grand rounds, to Carla to compose a spreadsheet to identify training opportunities.

A listserv for participants at the Feb 11 meeting and other interested people who become involved will be started by the Medical Home Project at the University of Washington to share information related to these activities. Contact at the Benton-Franklin Health District (carlap@bfhd.wa.gov) or Kate Orville (orville@uw.edu) at the UW to be added to the "BF\_CYSHCN" listserv.

#### APPENDICES:

- Invitation to CAM Meeting
- Meeting Agenda
- Participant List
- Tiers to Autism Diagnosis Pyramid
- Update on CADET's activities (from email with Dr. Scott Grewe)

These documents are posted at: [www.medicalhome.org/leadership/region\\_central.cfm#benton](http://www.medicalhome.org/leadership/region_central.cfm#benton)