

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

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

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"> • Kadlec formal assessment • Children’s Developmental Center 	<ul style="list-style-type: none"> • PT,OT, SLP
Autism Spectrum Evaluation and Diagnosis	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"> • CADET • Seattle Children’s Autism clinic • CHDD/UW Autism Clinic 	<ul style="list-style-type: none"> • Dr Scott Grewe clinical psychologist, SLP, motor therapist, Early intervention specialist

<u>Key to developmental screening tool acronyms:</u>	
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



WASHINGTON COMBATING AUTISM ADVISORY COUNCIL

Community Asset Mapping Project



We need you!

Your participation is key to developing a coordinated team approach to screening, assessment and treatment of autism and other developmental delays.

You are invited to our first meeting to be held on Friday, February 11th at United Way from 9:00 am - 1:00 pm. Light refreshments served.

To participate in this project, please RSVP to Carla Prock CSHCN Coordinator at (509) 460-4225 or e-mail to: carlap@bfhd.wa.gov by Tuesday, February 8th.



*Responding to
Autism Center*

Benton and Franklin Counties are participating in a pilot project with the Washington State Department of Health (DOH) and the University of Washington's Leadership Education in Neurodevelopmental Disabilities and Related Disorders (LEND) Program.*

Together we will evaluate our community's current method of screening, assessment, and referral to services and resources for children with suspected developmental delays, like autism.

Project goal

Develop a coordinated team approach to ensure children with suspected developmental delays, like autism, get appropriate resources and services in an efficient and timely manner.

What we will do

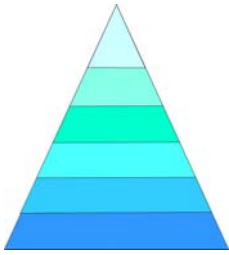
DOH and LEND will lead a half day meeting with families, support organizations, and education, behavior, and medical professionals to:

1. Define our community's current process of screening, assessment and referral to services and resources.
2. Determine what works well and what could be improved.
3. Establish a plan to:
 - a. Address issues with the current process.
 - b. Identify trainings or technical support that will increase knowledge and skills to improve our process.
 - c. Revisit, evaluate, and revise our plan.

Desired outcome

- Community understands the importance of all children getting early screening for developmental delays.
- More people can do early screenings.
- More people can refer for early intervention services.
- Community knows best place to send families for diagnosis.
- Families and service providers know where to go for resources and services.

*Funding for this project is provided by the Washington State "Autism Awareness: Partnership for Change" grant and the "LEND Combats Autism in Washington State" grant. The Combating Autism Advisory Council supports the work of the two grants and was instrumental in developing the Community Asset Mapping Project.



WASHINGTON COMBATING AUTISM ADVISORY COUNCIL

Benton-Franklin

Community Asset Mapping Project

AGENDA 9 AM – 1 PM

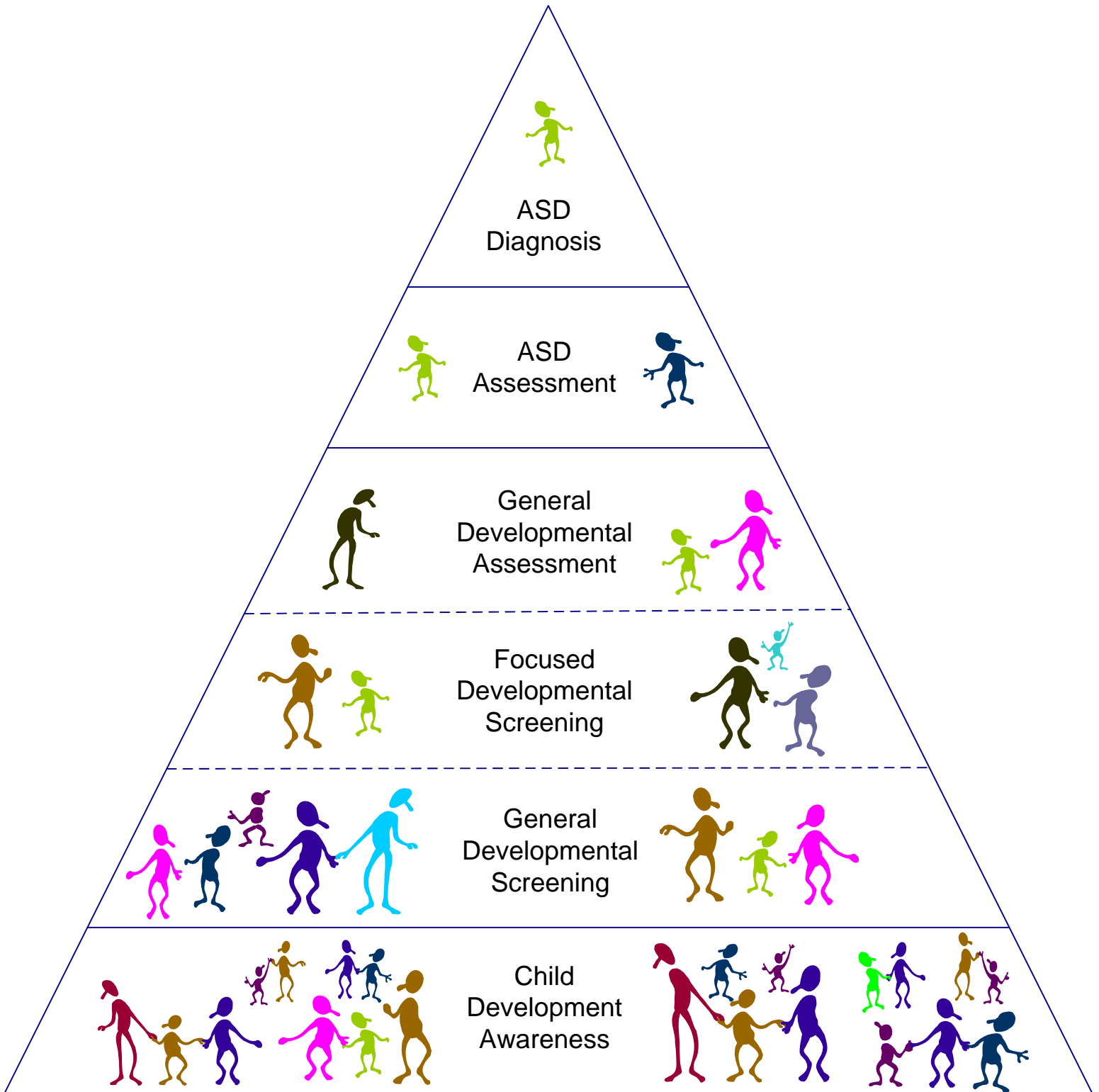
February 11, 2011

9:00 – 9:20	Welcome & Introductions
9:20 – 9:40	Overview of Community Asset Mapping Project Introduce the Tiers to Autism Diagnosis Pyramid
9:40 – 9:55	Parent Story: Why It Matters
9:55 – 10:10	BREAK
10:10 – 12:00	Benton-Franklin Community Asset Mapping <ul style="list-style-type: none">• Identify current community systems for ASD awareness, screening, assessment, diagnosis and referral.• Identify the gaps in services for children with ASD & their families.
12:00 – 12:15	BREAK
12:15 – 12:50	Benton-Franklin Plan - Building on our Assets & Identifying Next Steps <ul style="list-style-type: none">• Establish our priorities and next steps.• Identify a community member as a lead for each priority.
12:50 – 1:00	Wrap-up Complete Evaluation

Participants
Benton-Franklin Community Asset Mapping Meeting
Friday, February 11, 2011

Name	Position	Organization
Carla Prock	CSHCN Coordinator	Benton-Franklin Health District
Melissa Brooks	RN, Parent Resource Coordinator	Responding to Autism Center
Christine Lindgren	Director, Responding to Autism Center	Responding to Autism Center
Gina Rees	Nurse, LWP Peds/Parent	LWP Pediatrics
Michelle Smith	Community Support Manager	Lourdes Counseling
Betsy Colburn	CDC Autism	Children's Developmental Center
Jonna Hansmeier	CDC Program Director	Children's Developmental Center
Sherry Mashburn		WA PAVE
Randy Way		CDC Board Sylvan Learning
Kristy Wessels	ASW President	Autism Society of WA
Terry Buck	DDD/CRM	Division of Developmental Disabilities
Karen Hayes	ED	Kadlec Neuro Resource Center
Nita Kamphuis	Ass't Special Ed Director	Richland School District
Paolo de Vera	Pediatrician	Lourdes
Lisa Brauderick	Therapy Supervisor, SLP	Kadlec Regional Medical Center
Jennifer Wall	Public Health Nurse, CSHCN	Benton-Franklin Health District
Heather Espinoza	Autism Specialist	Pasco School District
Judy Westsik	ED	The Arc of Tri-Cities
Amanda Beers	Parent	
Carol Miller	WA Autism Project Coordinator	WA Dept of Health, CSHCN Program
Kate Orville	Co-Director Medical Home Project	UW Center on Human Dev & Disability
Amy Carlsen	Family Faculty	UW Center on Human Dev & Disability

Tiers to Autism Spectrum Disorders (ASD)* Diagnosis and Referral of Other Disorders



University of
Washington
LEND Program



Combating Autism Advisory Council

Updated 8/10/10

Tiers to Autism Spectrum Disorder Diagnosis and Referral of Other Developmental Disabilities

LEVEL	DESCRIPTION	EXAMPLES
<p>Child Development Awareness</p>	<p>Promote parent, provider, and community awareness of typical child developmental signs that may suggest a developmental concern to assure the well-being of children and their families and the early identification of developmental disabilities.</p>	<p>WA State:</p> <ul style="list-style-type: none"> ▪ Child Profile ▪ WA State Well Child Exam Forms (EPSDT) Checklists and Charts: ▪ Learn the Signs. Act Early. www.cdc.gov/ncbddd/autism/actearly; ▪ www.autismspeaks.org ▪ AAP Checklists – Bright Futures http://brightfutures.aap.org/
<p>General Developmental Screening</p>	<p>Routine surveillance and repeated screening of developmental performance within well-child visits following AAP guidelines and typical community settings to identify children at risk for developmental delays.</p>	<p>AAP recommends developmental surveillance at well-child visits: 9, 18, 24, 30 months</p> <ul style="list-style-type: none"> ▪ Parent Evaluation of Developmental Status (PEDS) ▪ Ages & Stages Questionnaire (ASQ-III) ▪ Child Development Inventories (CDI) <p>www.aap.org/published/autismtoolkit.cfm</p>
<p>Focused Developmental Screening</p>	<p>Targeted developmental screening using validated tools to identify children needing further evaluation for specific developmental concerns.</p>	<ul style="list-style-type: none"> ▪ Developmental Assessment of Young Children (DAYC) ▪ ASQ – Social Emotional (ASQ-SE) ▪ Modified Checklist for Autism in Toddlers (M-CHAT) and follow-up questions (AAP recommends at 18/24 months) ▪ Screening Tool for Autism in Two-Year Olds (STAT) ▪ Childhood Autism Rating Scale (CARS)
<p>General Developmental Assessment</p>	<p>General developmental assessment by providers with specific training and experience, using validated tools to provide differential diagnosis for developmental delay. Identify children who need referral for an assessment specific to autism.</p>	<p>Standardized assessments of:</p> <ul style="list-style-type: none"> ▪ Cognition ▪ Communication/Language Skills ▪ Motor Skills ▪ Adaptive Skills ▪ Social/Emotional Skills
<p>ASD Assessment</p>	<p>In-depth functional assessment for autism by clinicians with specific training and experience; use of validated tools to make an ASD diagnosis.</p>	<ul style="list-style-type: none"> ▪ Autism Diagnostic Observation Schedule (ADOS) ▪ Autism Diagnosis Interview (ADI-R) ▪ Childhood Autism Rating Scale (CARS) ▪ DSM-IV Criteria
<p>ASD Diagnosis</p>	<p>WAC 388-823-0500 states who can diagnose.</p>	<ul style="list-style-type: none"> ▪ Neurologist, Psychiatrist, Licensed Psychologist, Developmental Pediatrician

Feb 9, 2011

I will give you a quick overview of what is going on in my world with respect to autism services, though – feel free to share this with your group.

1. CADET continues to do twice-monthly evaluation days, seeing two children each day. We are seeing children ages 18 months to about 9 years. We have an early intervention/autism specialist (Nicki Mack), speech/language pathologist (Renee Schaefer), motor therapist (Laura McGuckin), and myself. We also continue to have a bilingual psychology graduate student working with us during our evaluations, and he is also working with several families, post-evaluation, regarding behavior management. The Children's Developmental Center (CDC) also continues to run a parent-based behavior management training (Children's Behavior Management Workshop; CBMW) 2-3 times per year. I supervise these activities in my role as Clinical Director.

2. Dr. Paul Strand, an associate professor of psychology at WSU Tri-Cities, and I were awarded funding for 2 psychology graduate student assistantships for academic year '11-'12. This is our fourth year of funding for this training experience. One of the students for next year is bilingual and will hopefully be spending some of her time at the Responding to Autism Center. I e-mailed Christine Lindgren to initiate discussions about collaborative efforts; we will be working with her to discuss how best to extend services in our community through the availability of trainees.

3. The CDC was awarded funding to have Nicki Mack go through the RDI training/certification process, which should help expand treatment services in our area. The Autism classroom at the CDC has also expanded – they now have a morning and an afternoon early intervention program. The CDC is also in the process of becoming a formal neurodevelopmental center and meeting with a local pediatrician, who will become the Medical Director. This should open some additional doors for service provision.

4. Peter Stewart, a clinical child psychologist and my officemate, and I are in the process of recruiting for a third child psychologist to join our practice. Our emphasis in this recruitment will be someone with interest/expertise treating youth with ASD's.

I think that captures what is going on, at least as far as I am involved. I'm sorry I won't be able to attend the meeting on Friday, but I look forward to hearing from you about the outcome.

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