



# **Community Asset Mapping: Building Relationships to Improve Early Autism Diagnosis and Connection to Services**

**2022 SPARC Peer to Peer Exchange  
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- Director, WA Medical Home Partnerships Project for Children and Youth with Special Healthcare Needs (MHPP)
- Housed at UW Center on Human Development & Disability
- MHPP funded by WA State Dept. of Health, Title V as technical assistance center CSHCN related MCH National Performance Measures
- Consultation, resources and linkages to community partners developing medical homes and easily accessible, coordinated systems of care – esp Autism in past 10 years
- Serve as Faculty on Project ECHO Autism WA and ECHO for Resource Navigation for I/DD
- Parent

# Margaret Mead

*“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.”*



- Photo by [Chang Duong](#) on [Unsplash](#)

# Background

- WA State had initial HRSA Autism grant 2008-2013 – Partnership with UW LEND\* and WA Dept. of Health, Dx Centers and counties

\* Leadership Education in Neurodevelopmental and Related Disabilities

- Goal: Increase early ID and access to services
- Advisory Council Training and Access Subcommittees
  - Where are Multi-Disciplinary Diagnostic teams ?
  - What is “Gold Standard”- rural vs. urban communities vs “Good enough” – not let perfection prevent most children from Dx
  - How to support each other across the state






# Next Steps – Talking Isn't Enough

- Parent and nonprofit Director Dawn Sidell, RN provided funds to bring partners together
  - Learn what Dx teams are doing
  - Begin ID of effective and efficient strategies and tools to fit different community needs
- Rural community center Children's Village hosted and Advisory Board members planned
- Invited broad base of stakeholders to attend extra day summit outside of Advisory Bd meeting

# Keynotes Inspire New Thinking

- 1) Dr. Daniel Coury Medical Director of Autism Treatment Network (basics of ASD dx and frequent medical issues) and work with the Ohio AAP to promote developmental screening
- 2) Dr. Glenn Tripp – expanding idea of who can diagnose- experienced clinician (from a variety of backgrounds) with knowledge of child development AND autism, working in partnership with a multidisciplinary team.



# Brainstorming: Unclogging the System

Could communities be part of the solution to reduce wait times?

If communities knew what they had in place from screening to diagnosis and who was doing what, could they reduce the number of children sent to the few Dx centers?

Could they send better assessment information with the children? Could they **MAKE** the diagnosis?

→ Tiered Approach to ASD Dx and Referral Pyramid

# Tiers to Autism Spectrum Disorders (ASD) Diagnosis and Referral Pyramid





## Tiers to Autism Spectrum Disorder Diagnosis & Referral of Other Developmental Disabilities

LEVEL	DESCRIPTION	EXAMPLES
<b>Child Developmental Awareness</b>	Promote parent, provider, and community awareness of typical child development and signs that may suggest a developmental concern to assure the well-being of children and their families and the early identification of developmental disabilities.	WA State: Child Profile Checklists and Charts: <ul style="list-style-type: none"> <li>• <a href="#">Learn the Signs. Act Early.</a></li> <li>• <a href="#">Autism Speaks</a></li> <li>• AAP Checklists - <a href="#">Bright Futures</a></li> </ul>
<b>General Developmental Screening</b>	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.	AAP recommends developmental surveillance at well-child visits: 9, 18, 24, 30 mos. <ul style="list-style-type: none"> <li>• Parent Evaluation of Developmental Status (PEDS)</li> <li>• Ages &amp; Stages Questionnaire (ASQ-3)</li> <li>• Child Development Inventories (CDI)</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>• Developmental Assessment of Young Children (DAYC)</li> <li>• ASQ -Social Emotional (ASQ-SE)</li> <li>• Modified Checklist for Autism in Toddlers-Revised (M-CHAT-R/F) Checklist and follow-up. (AAP recommends at 18/24 months)</li> <li>• Screening Tool for Autism in Two-Year Olds (STAT)</li> <li>• Childhood Autism Rating Scale (CARS)</li> </ul>
<b>General Developmental Assessment</b>	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.	Standardized assessments of: <ul style="list-style-type: none"> <li>• Cognition</li> <li>• Communication/Language Skills</li> <li>• Motor Skills</li> <li>• Adaptive Skills</li> <li>• Social/Emotional Skills</li> </ul>
<b>ASD Assessment</b>	In-depth functional assessment for autism by clinicians with specific training and experience; use of validated tools to make an ASD diagnosis.	<ul style="list-style-type: none"> <li>• Autism Diagnostic Observation Schedule (ADOS-2)</li> <li>• Autism Diagnosis Interview (ADI-R)</li> <li>• Childhood Autism Rating Scale (CARS)</li> <li>• DSM-5 Criteria</li> </ul>

# Tiers to Autism Diagnosis Pyramid Model

- Goal try out model to see if it can:
  - Make steps to autism screening and Dx clearer for families and providers
  - Reduce bottlenecks at MDT diagnostic centers
  - Help more kids get faster, accurate Dx
  - Identify the training and technical assistance needs of communities to improve the identification and diagnosis of ASDs

# Community Asset Mapping (CAM) Goal

Establish coordinated and accessible systems for families to receive developmental screening and help through a diagnostic process for ASD and other developmental concerns.



# Community Mapping -- JOY

- Community mapping is the process and product of a community getting together to map its own assets, values, beliefs or any other self-selected variable. It is about mapping by the community for the community using relatively informal processes.
  - In: [\*The SAGE Encyclopedia of Action Research\*](#), Edited by: David Coghlan; Mary Brydon-Miller
- Builds on individual and community motivation and fed by joy in creation





# Community Asset Mapping Prep work

- Selected facilitated pilot communities meeting the identified criteria including community champions
- Community champion/ liaison invited key community stake-holders from public schools, Birth to 3, Parent to Parent, pediatric medicine, Head Start/ECEAP, etc. to participate.
- Champions
  - County 1- MD, County 2- EI/parent and MD, County 3 – Public health nurse

# CAM Community Meetings

- Introductions
- Map out resources for identifying and serving children with ASD and other Neurodevelopmental disabilities
- ID 2 priorities for expanding early identification capacity locally
- Identify next action steps to make improvements — esp someone to pull together next meeting



# Summary of Needs

- Community “road maps” for parents and providers to navigate local systems.
- Increase child care provider awareness & knowledge of development red-flags how to talk with parents when a developmental concern is observed.
- Expand community provider knowledge, skill, and utilization of general screening tools (e.g. ASQ, SWYC) and ASD-specific screening tools (e.g. MCHAT)
- Training on autism evaluation, family resources and care management important
- Diagnosis to occur within the community if possible

# Early Lessons Learned

- Communities liked the Pyramid and found it a helpful organizing tool.
- Communities are hungry for the opportunity to have facilitated dialogues about coordinating ASD services and resources.
- Silos between medical, school, and mental health worlds- different languages and rules.
- Communities want ongoing communication with the TA team and central support as well as with other communities doing similar work



# Lessons Learned (continued)

- CAM Stakeholders meeting is just the “first pearl on the necklace.”
- Community champions and administrative support for the work critical to harnessing the enthusiasm and energy into concrete, ongoing action or efforts fade away
- Vital to include family members and autistic self-advocates as ongoing participants of the community discussions and next steps.
- Rural Lewis County example

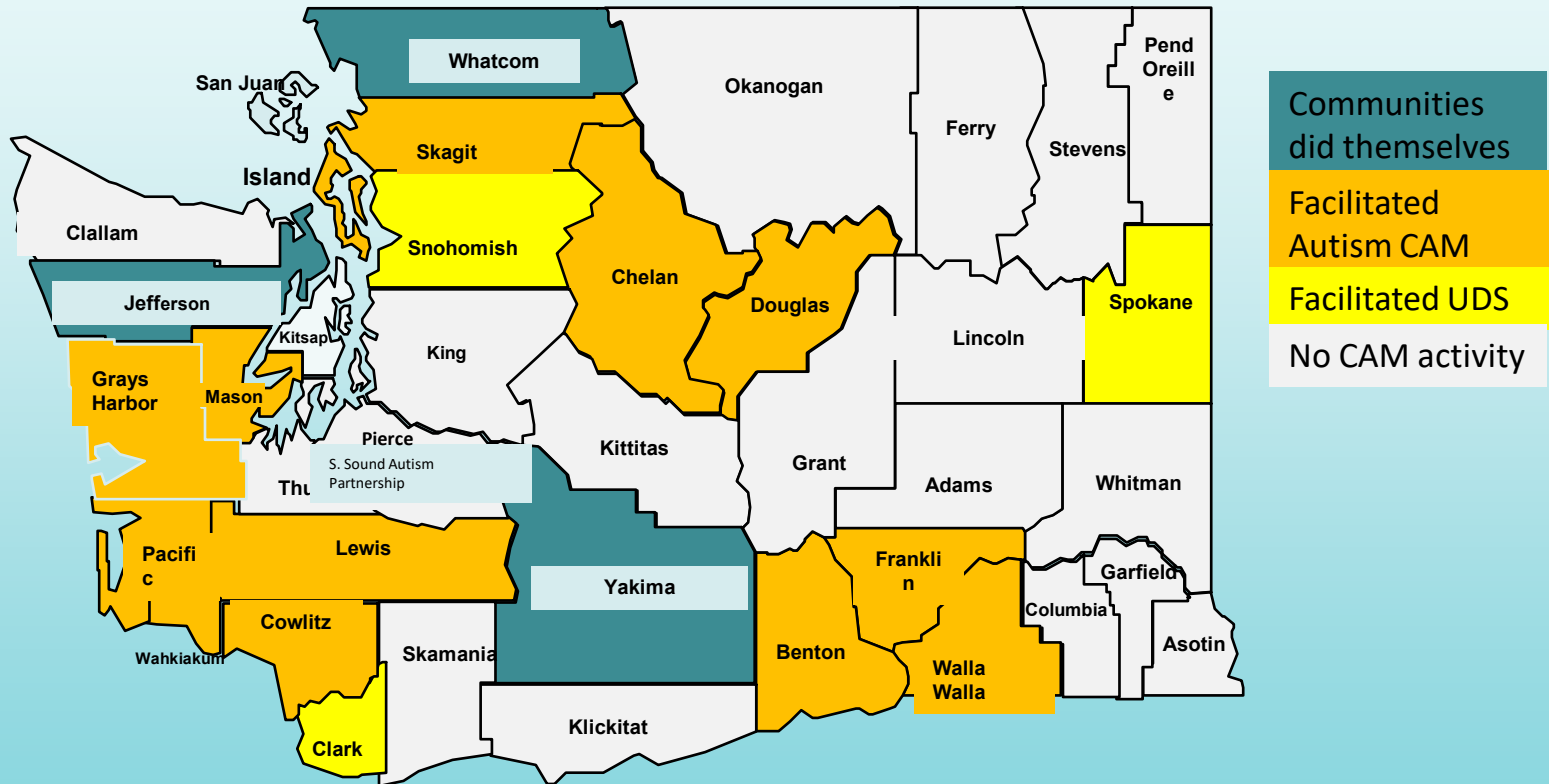
*Lewis County*

# Autism Coalition

- Monthly Coalition meeting
- Annual Autism Conference
- Cultivating Inclusion Campaign
- Family Resources Coordinator (LINK program)
- School and Medical Autism Review Team (SMART) <https://www.lcautism.org/>



# WA COMMUNITY ASSET MAPPING (CAM) FOR AUTISM OR UNIVERSAL DEVELOPMENTAL SCREENING (UDS)



7/10/2022

# CAM Changes Over Time

- Changes to CAM process- do more asset mapping advance prep work
- Some WA communities adapt for other topics like resources needed by families with young children, or care coordination
- Development of School Medical Autism Review Team (SMART) model → many communities start with ASD Assessment & Diagnostic tiers first



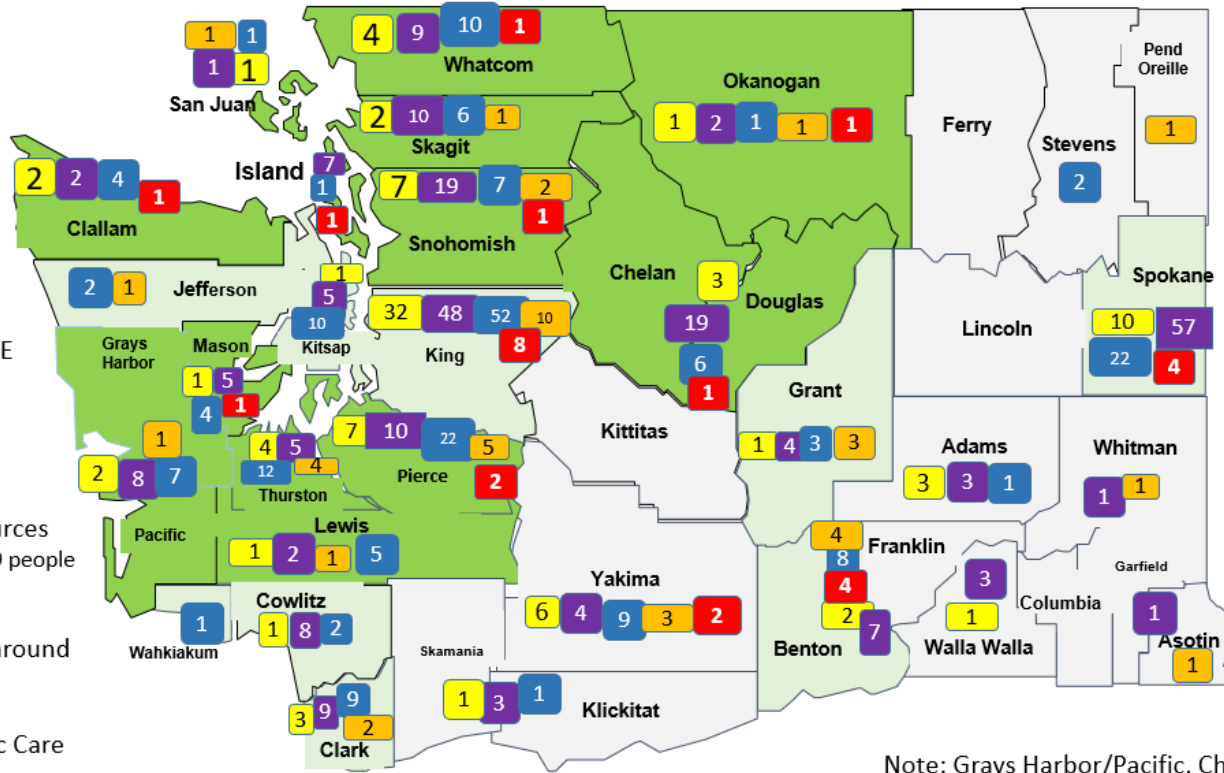
# Environmental Changes

- Changes in WA to who can diagnose- as of 2013, broadening group of PCPs can too- (lawsuit)
- Autism Center of Excellence (COE) training for PCPs- now virtual and use AAP/Pedialinks [“Identifying and Caring for Children with Autism Spectrum : A Course for Pediatric Clinicians”](#) online CME 1 Autism course
- COE training not enough to get PCPs to DX
- Title V funds used to bring Dr. Kristin Sohl from Univ of Missouri to talk about how to start Project ECHO in WA

# Project ECHO grows to INCLUDE

- WA State Legislature funds Project ECHO WA for PCPs . Yr 1 - 28 people, Yr 2 - 72, Yr 3 - 83
- Success → Health Care Authority (Medicaid) funds:
  - ECHO I/DD Wraparound
  - Resource Navigation
  - Med management/psych care.
- Co-occurring mental health institute fall 2022
- RUBI parent training and more

# Growth of Autism Training and Support Network in WA



School and Medical Autism Review Teams (SMART)

- Established or developing SMART Team/Network
- Interest in SMART




- 85** # ECHO Autism COE (23/39 counties)
- 255** # Autism COEs (31/39 counties)
- 222** # ECHO IDD Resources (27/39 counties) (& 9 people based in all WA)
- 58** #ECHO IDD Wraparound (21/39 counties)
- 27** # ECHO Psychiatric Care (13/39 counties)

5/5/2022

Note: Grays Harbor/Pacific, Chelan/ Douglas, Benton/Franklin, Skamania/Klickitat and Garfield/Asotin are paired with each other

# Growing Together

## Shayla's List

~~~ Financial ~~~	
<p><b>Prescription for Diapers</b></p> 	<p><i>What is it?</i> For children ages 3 years and older, diapers can be covered by medical insurance with a prescription.</p> <p><i>How to get it:</i> You will need an annual prescription for diapers with a diagnostic code of bowel and bladder incontinence. A medical supply company will provide you with the diapers.</p>
<p><b>Charity Care and Financial Assistance at Washington State Hospitals</b></p> 	<p><i>What is it?</i> Washington's hospitals are committed to ensuring patients get the hospital care they need regardless of their ability to pay for that care. Charity care eligibility is based on family size and income. Providing health care to those that cannot afford to pay is part of the mission of Washington's hospitals. State law requires hospitals to provide free and discounted inpatient and outpatient care. Each hospital is responsible for maintaining its own charity care program.</p> <p><i>How to get it:</i> Reach out to the hospital's charity care/financial assistance program for information on eligibility and to get the application. Below are links to information on the children's hospitals programs:            Seattle Children's Hospital  <a href="https://www.seattlechildrens.org/clinics/paying-for-care/financial-assistance/">https://www.seattlechildrens.org/clinics/paying-for-care/financial-assistance/</a>            Sacred Heart Hospital  <a href="https://www.hshs.org/SacredHeart/Patients-Guests/Patient-Financial-Services/Patient-Financial-Assistance">https://www.hshs.org/SacredHeart/Patients-Guests/Patient-Financial-Services/Patient-Financial-Assistance</a>            Mary Bridge Children's (part of <b>Multicare</b>)  <a href="https://www.multicare.org/patient-resources/financial-assistance/">https://www.multicare.org/patient-resources/financial-assistance/</a></p>
<p><b>Supplemental Security Income (SSI)</b></p> 	<p><i>What is it?</i> Supplemental Security Income (SSI) is a federal program that gives payments to children and adults with disabilities who have limited income and resources. The cash payments can be used to meet basic needs for food, clothing, and shelter.</p> <p><i>How to get it:</i> Call toll-free at 1-800-772-1213 (TTY 1-800-325-0778) between 8:00 am – 7:00 pm., Monday through Friday.</p>

- UW INCLUDE
- Cross recruitment
- Early Intervention Centers collaboration with COEs; Latino CHWs training
- Quick Start Guide for Autism COEs
- “Sister” ECHOs



# Respecting and Growing Diversity and Inclusion

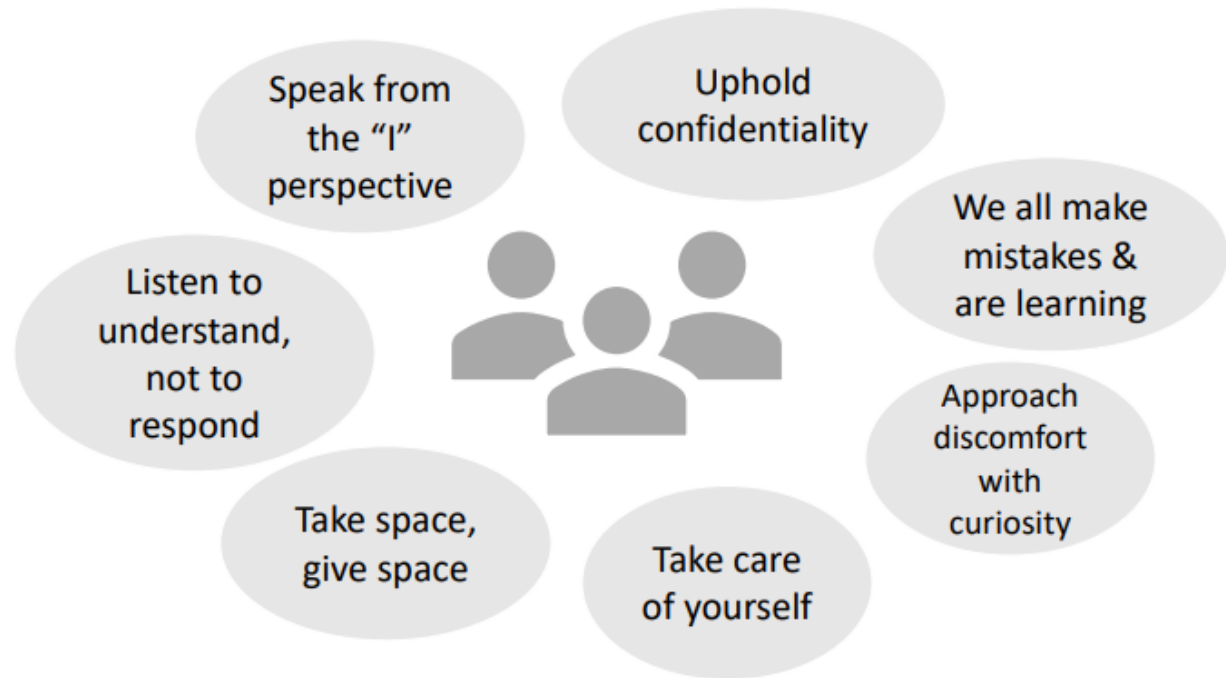
Of lived experience, professional expertise, geography, racial/ethnic/linguistic communities

ECHO: All Teach, All Learn

- Family Faculty and Speakers
- Self-Advocate Faculty and Speakers
- ECHO facilitators and faculty
- 5<sup>th</sup> Wednesday ECHO sessions- June 29<sup>th</sup> on ABA

# Advancing Health Equity through Integrated Care ECHO - National Council for Mental Wellbeing

## Session Norms



We have been socialized to believe that it is not polite to talk about oppression, race and racism (and other -isms) – hearing about & talking about these things may bring up feelings of discomfort.

We ask ourselves and participants to be mindful of assumptions, and biases during this presentation.

We ask ourselves and participants to be aware of multiple identities, backgrounds and perspectives in our virtual space.

# WA Resources

- WA CSHCN Community Asset Mapping <https://medicalhome.org/stateinitiatives/community-asset-mapping/>
- WA SMART Teams: <https://medicalhome.org/school-medical-autism-review-team-smart/>
- WA Project ECHO Autism: <https://uw-ctu.org/echo/>
- Shayla' List [medicalhome.org](https://medicalhome.org)

# National Resources

- American Academy of Pediatrics' (AAP) PediaLink course [“Identifying and Caring for Children with Autism Spectrum Disorder: A Course for Pediatric Clinicians”](#) (6.5 hours CME 1)
- ABCD Toolkit: Community Building Principles and Action Steps- <https://resources.depaul.edu/abcd-institute/resources/Documents/CommunityBuildingPrinciplesandActionStepsChart.pdf>
- Community Asset Mapping tool from National Center for Farmworker Health (2021) [http://www.ncfh.org/uploads/3/8/6/8/38685499/ncfh\\_asset\\_mapping\\_tool.pdf](http://www.ncfh.org/uploads/3/8/6/8/38685499/ncfh_asset_mapping_tool.pdf)



# And it all started with...

- A HRSA grant providing infrastructure and seed money
- Committed families, individuals, providers and their organizations who developed relationships and trust that we could make a difference
- Building on our strengths and learning from each other.

# Thank You!



Questions?

Reactions?

How might  
Community Asset  
Mapping work for  
you (or are you  
already doing it)?