



Children and Youth with Special Health Needs in Rural Communities

Wednesday, November 17, 2010

Presented by:

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Moderators:

- **Deidre Washington-Jones :** Senior Public Health Analyst
- **Julia Bryan:** Senior Public Health Analyst

Technology-Based Services in a Rural State

Brent A. Askvig, Ph.D.

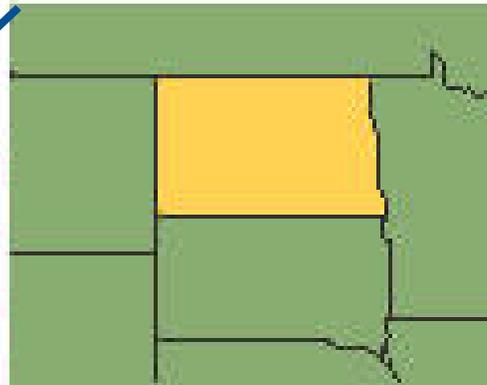
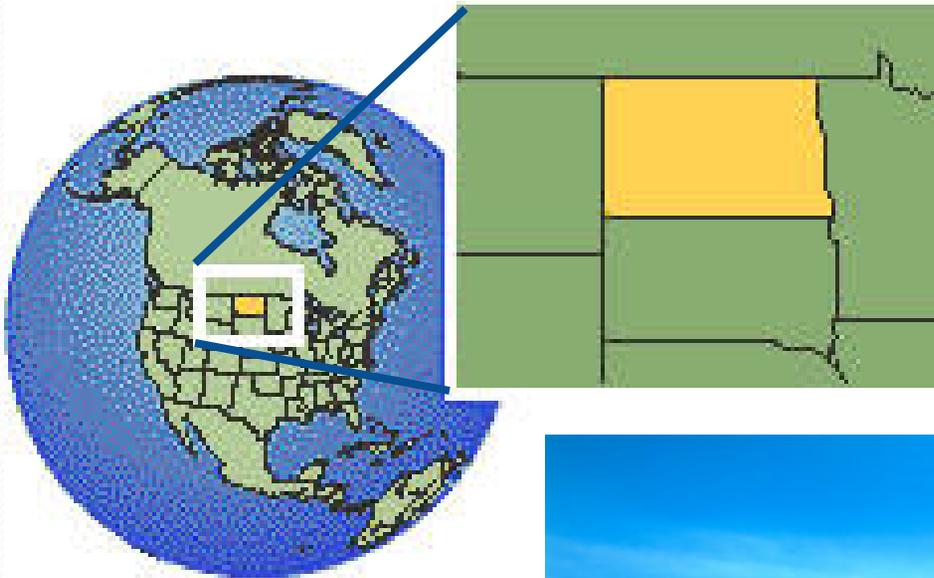
North Dakota Center for Persons with Disabilities

A University Center of Excellence at

Minot State University



North Dakota



68,976 square miles (17/56)

636,677 population (49/50)

9.3 people/square mile

(47/50)

2/3 of counties are “frontier”





Challenges in a Rural State

- Distance/geography
- Weather
- Lack of service sites
- Lack of professionals



NDCPD's Approach

- Use excellent state connectivity
- Maximize professional time
- Utilize top notch technology
- Safeguard privacy/security

Examples

- Distance audiology screening
- Remote realtime online captioning
- Online speech language therapy
- Online health/wellness training for individuals with intellectual disabilities
- Technology-based team diagnostics in ASD
- Development of national protocol for early childhood audiological diagnostic assessments

Autism Diagnostic Clinic



Diagnostic Negotiation/Discussion



Report Writing – Using Technology

- easily accessible (Sharepoint)
- deadlines
- type as you talk
- dictation on car ride home
- pre-scheduled post diagnostic meeting

The screenshot shows a SharePoint 2007 web application for the 'Great Plains Autism Treatment Program'. The interface includes a navigation sidebar on the left with sections for 'View All Site Content', 'Pictures', 'Documents', 'Links', 'Calendar', 'Tasks', 'Discussions', and 'Sites'. The main content area is divided into several sections: 'Updates' with a 'Williston Diagnostic Clinic Files' update, a 'Dorgan Update' by SHARPCENTjwendy, and an 'Add new announcement' link; 'Working Documents' with a table of documents; 'Tasks' with a table of tasks; and 'Calendar' with a message about upcoming events. The 'Writing Team' sidebar on the right lists team members: Ashby, Steve; Field, Bryce; Herfer, Jennifer; Hergen, Gina; and Thomas, Wendy, with their business phone and email addresses.

Title	Modified	Modified By	Checked Out To
Minutes	1/9/2008 2:32 PM	SHARPCENTjwick	
Diagnostic and Treatment Matrix	4/1/2008 11:21 AM	SHARPCENTjenniferh	
Autism Advisory Council	2/12/2008 2:44 PM	SHARPCENTjgrah	
Dr. Rick Lubic Diagnostic	11/26/2008 11:00 AM	SHARPCENTjwendy	
Williston Diagnostic Clinic Client Folder	3/12/2008 2:04 PM	SHARPCENTjwendy	
Minot Diagnostic Clinic	6/3/2008 12:46 PM	SHARPCENTjwendy	
Dorgan Talking Points - PHIL	6/17/2008 12:09 PM	SHARPCENTjwendy	
GPAT Request for Full IRB Review	8/11/2008 2:30 PM	SHARPCENTjwendy	
IRB CONSENT FORM	8/11/2008 2:47 PM	SHARPCENTjwendy	
Stress and money questionnaire weekly	3/4/2009 9:25 AM	SHARPCENTjwendy	
Stress and money questionnaire weekly	8/27/2008 3:43 PM	SHARPCENTjwendy	
Stress and money questionnaire pre post	8/11/2008 2:38 PM	SHARPCENTjwendy	
GPAT application cover lr _1_	8/2/2008 9:38 AM	SHARPCENTjwendy	
GPAT Application form _2_	8/12/2008 2:33 PM	SHARPCENTjwendy	
Blending Technology with Interdisciplinary Teams for Assessment	10/13/2008 8:46 AM	SHARPCENTjwendy	SHARPCENTjwendy



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For questions about the hardware and software components, contact Mr. Steve Peterson at 1-800-233-1737 or steve.peterson@minotstateu.edu

Health Care for CSHCN in Rural America

Victoria A. Freeman, RN, DrPH

With credit to former colleagues Asheley Skinner and Becky Slifkin

North Carolina Rural Health Research & Policy Analysis Center

Cecil G. Sheps Center for Health Services Research

University of North Carolina at Chapel Hill

Challenges for CSHCN and Families...

No Matter Where They Live

Diagnosis and Treatment

Screening

Specialty Care

Primary Care

Financial Support

Insurance

Employment

Special Programs

Family and Child Support

Transportation

Case Management

Respite

Transition Services

What do we know about rural CSHCN?

Data: National Survey of Children with Special Health Needs (2000-2002)

Definition of Rural: Residence in a nonmetropolitan statistical area (rural) vs. a metropolitan area (urban).

Analysis: Compares rural children to urban children
Uses statistical modeling to control for other factors to see if the rural-urban differences remain

OR = Odds Ratio

aOR = adjusted Odds Ratio that accounts for differences in poverty status, insurance, race and maternal education.

Skinner AC, Slifkin RT. Rural/urban differences in barriers to and burden of care for children with special health care needs. *J Rural Hlth* 2007;23:150-7.

Characteristics of Respondents

Residence – 19.3% live in rural areas

Rural respondents are more likely to:

- have incomes
 - under 200% of FPL (29.0% vs 18.0%)
 - under 100% of FPL (18.4% vs 12.5%)
- be uninsured (13.9% vs 11.1%)
- be white (83.4% vs 73.1%)
- maternal education
 - less than high school (17.4% vs 14.4%)
 - high school diploma only (36.0% vs 28.8%)

Access to a Usual Source Care

- Rural CSHCN are as likely as urban CSHCN to have a usual source of care but the source is different.

MORE likely to use a clinic or health center (aOR=1.36)

LESS likely to use a private doctor (aOR=0.85)

MORE likely to see a general doctor (aOR=1.99) or mid-level (aOR=2.05)

LESS likely to see a pediatrician (aOR=0.50)

When population characteristics (poverty, insurance, race, mother's education) are controlled,

differences in usual source of care persist.

Barriers to Care

- Parents of rural CSHCN are more likely to report delaying care (OR=1.25, aOR=1.01)

Specific barriers:

MORE likely to report

Care was not available in their area (aOR=1.81)

Could not afford care (aOR=1.40)

LESS likely to report

Could not reach a provider on the phone (aOR=0.55)

Not getting approval for care from a health plan (aOR=0.71)

Waiting too long at the office (aOR=0.63)

Having language, communication, cultural problems (aOR=0.38)

When population characteristics are controlled...

Differences in delay of care **go away**

Differences in barriers **persist**

Which Services for Rural **Children** Are a Challenge?

Unmet Need

Without considering population characteristics...

- More likely to have unmet needs for:
Dental care (OR=1.28)
- Less likely to have unmet need for:
Therapy (OR=0.64)

After considering population characteristics...

- Less likely to have unmet need for:
Therapy (aOR=0.59)

No difference (adjusted or unadjusted) for any care or for routine care, specialty care, prescriptions or mental health care specifically.

Which Services for Rural **Children** Are a Challenge? Barriers

Without considering population characteristics...

- More likely to report care **not available in area/transportation**:
 - Any care (OR=1.75) Specialty care (OR=1.90)
 - Dental care (OR=1.86) Therapy (OR=2.83)
- More likely to report care **not at convenient time**:
 - Prescriptions (OR=6.07)

After considering population characteristics...

- More likely to report care **not available in area/transportation** as a barrier:
 - Any care (aOR=1.58)
 - Therapy (aOR=2.50)
 - Prescriptions (new) (aOR=3.58)
- More likely to report care **not at convenient time** – No differences

Which Services for Rural **Children** Are a Challenge?

Barriers

Without considering population characteristics...

- Less likely to report care **not at convenient time**:
Therapy (OR=0.35)
- Less likely to report a **health plan problem**
Specialty care (OR=0.52)

After considering population characteristics...

- Less likely to report care **not at convenient time**:
Therapy (aOR=0.35)
- Less likely to report a **health plan problem**
Specialty care (aOR=0.49)

Which Services for Rural **Families** Are a Challenge?

Unmet Need

No difference (adjusted or unadjusted) for any care or for respite care, genetic counseling, family mental health/counseling specifically.

Which Services for Rural **Families** Are a Challenge? Barriers

Without considering population characteristics...

- More likely to report **care not available/transportation** as a barrier:
Any care (OR=1.57)
Mental health/counseling (OR=2.10)

After considering population characteristics...

- **Availability/transportation** differences go away
- More likely to report **cost** as a barrier:
Genetic counseling (aOR=2.69)

Which Services for Rural Families Are a Challenge? Barriers

Without considering population characteristics...

- Less likely to report that care **costs** too much:
Respite (OR=0.46)
- Less likely to report care **not at a convenient time**:
Any care (OR=0.41) Genetic counseling (OR=0.14)
Respite care (OR=0.26)
- Less likely to report **health plan problem**:
Family mental health/counseling (OR=0.47)

After considering population characteristics...

- Less likely to report that care **costs** too much:
Respite (aOR=0.36)
- Less likely to report care **not at a convenient time**:
Any care (aOR=0.43) Genetic counseling (aOR=0.15)

What is the burden?

- Rural parents were...

MORE likely to report

Financial problems caused by health care (OR=1.21)

Needing additional income for medical expenses (OR=1.19)

Provides care at home – only burden that remains higher after controlling for population characteristics (aOR=1.36)

Spending ≥ 5 hours providing care (OR=1.28)

Spending ≥ 2 hours arranging care (OR=1.19)

LESS likely to report – both persist after controlling for other factors

Family member had to cut work hours or stop work (aOR=0.88)

Family member stopped working due to child's health (aOR=0.82)

Summary

- Population characteristics and health system characteristics limit care.
Both are important.
Solutions differ.
- Economic opportunity
Poverty and uninsurance are consistent barriers.
Lack of opportunity extends beyond inability afford care.
- Health care system
Types of providers differ.
Lack of local availability and/or transportation are cited most often.
Specific aspects of health care are not an issue when there is no care.



Community Asset Mapping in Washington State Rural Communities

A Pilot Project of the
Washington State
Combating Autism Advisory Council

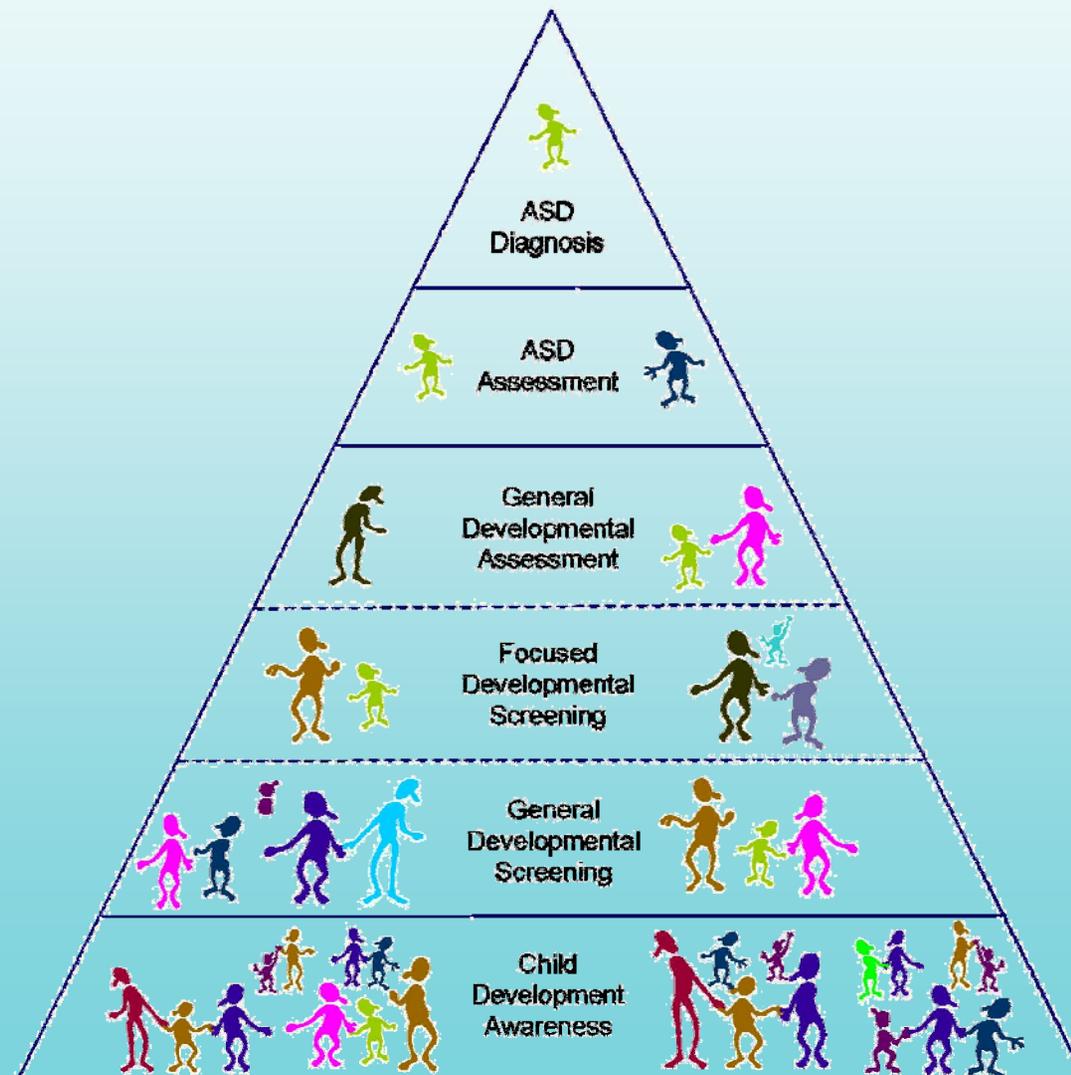
**Sponsored by the Washington State Department of Health Children with Special Health
Care Needs Program and the University of Washington Leadership Education in
Neurodevelopmental and Related Disabilities Program**



Partnerships

- The Children with Special Health Care Needs Program (CSHCN) and the University of Washington Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program partnered through two state Autism implementation grants to form the Combating Autism Advisory Council (CAAC).
- Community Asset Mapping comes out of the CAAC and is an approach we have used in WA state to improve the system of healthcare for children with special needs.

Tiers to Diagnosis





Tiers to Diagnosis Pyramid

**Serves as the framework
for discussions in our
communities.**



Goals

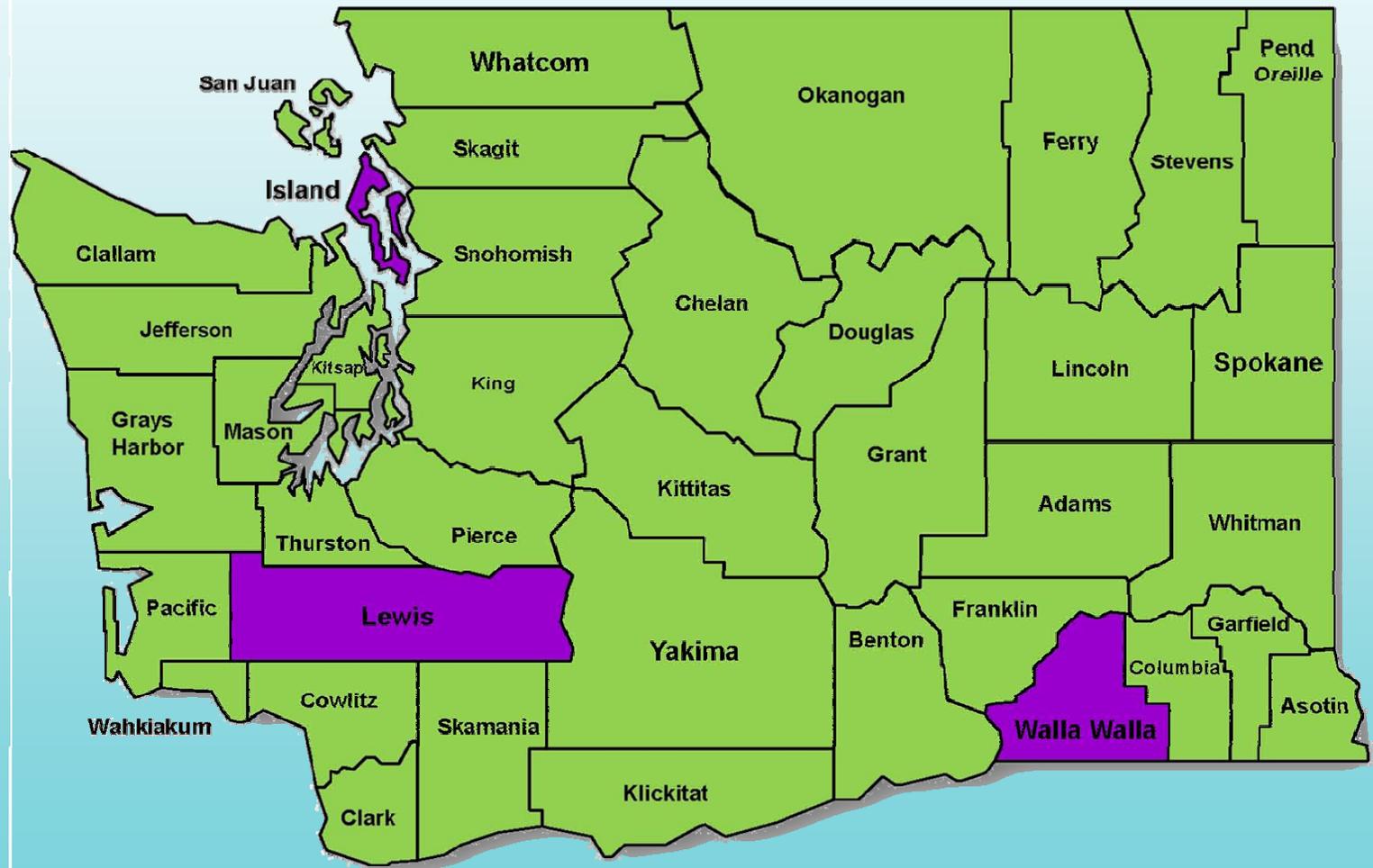
- Pilot this model to see if it can:
 - Make steps to autism diagnosis clearer for families and providers within their communities.
 - Reduce long waiting lists at diagnostic centers and possibly provide diagnosis within the community.
 - Identify the training and technical assistance needs of rural communities to improve the identification and diagnosis of ASDs.



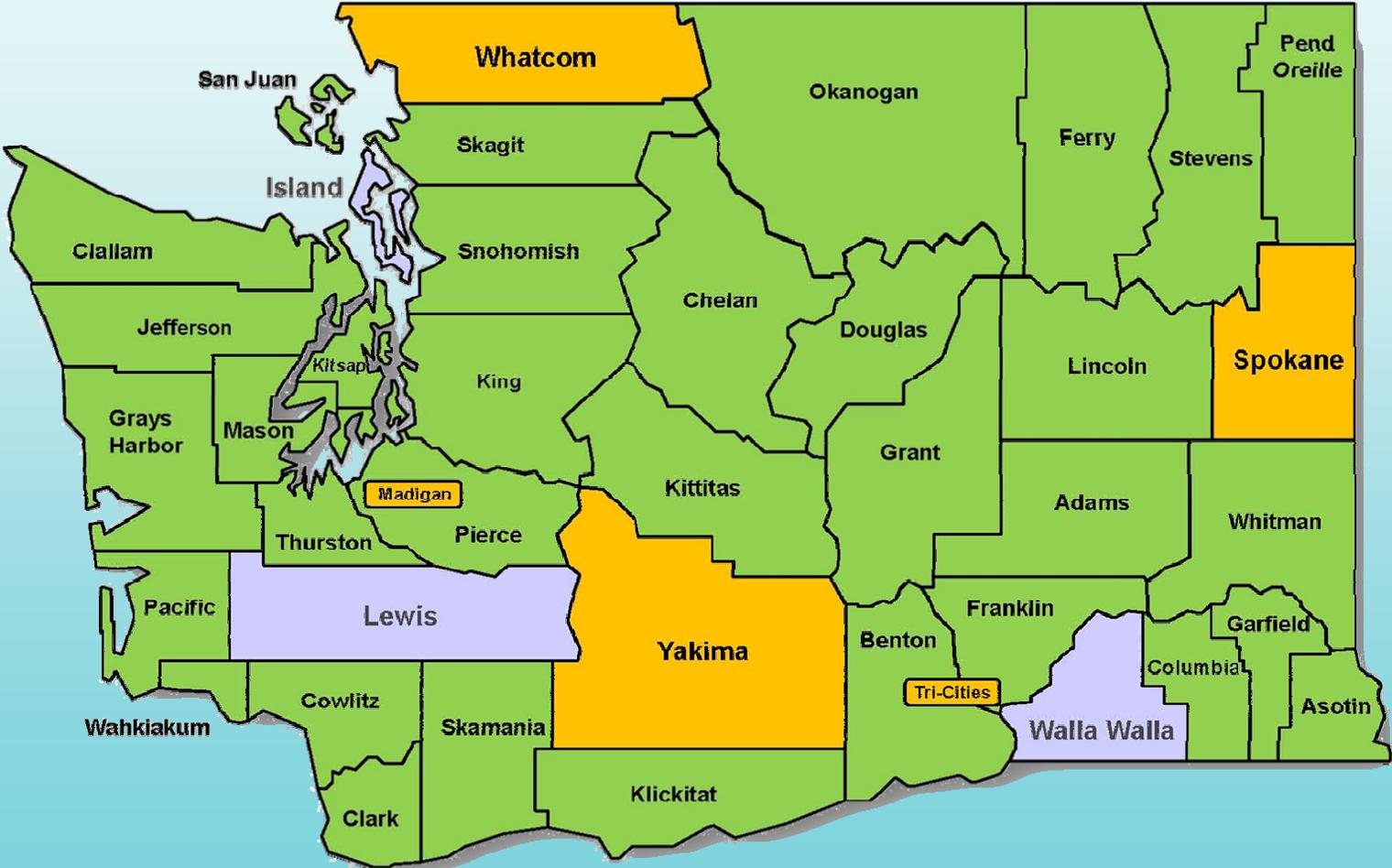
Community Asset Mapping Steps to Date

- Selected facilitated pilot communities meeting the identified criteria.
- Community liaison invited key community stakeholders from public schools, Birth to 3, Parent to Parent, pediatric medicine, Head Start/ECEAP, etc. to participate.
- Each community identified next priority steps and linked back to the Combating Autism Advisory Council for ongoing technical assistance.

Three Pilot Communities



Other Communities





Summary of Needs

- A community “road map” for parents and providers.
- Increase child care provider awareness and knowledge of development red-flags and training in how to talk with parents when a developmental concern is observed.
- Expand community provider knowledge, skill, and utilization of ASD screening tools such as MCHAT and others.
- Diagnosis to occur within the community.



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.
- They appreciate help from a technical assistance (TA) team, and it motivates forward action within the community.
- Communities want ongoing communication with the TA team and collaboration with the CAAC.



Lessons Learned (continued)

- For communities to be successful carrying out next steps they desire to build a community-based infrastructure and dedicated financial resources .
- Vital to include family members as ongoing participants of the community discussions and next steps.
- Communities also want to discuss building skill and capacity in providing evidence-based intervention services.



Next Steps in the Communities

- Each community is working to develop a “road map” for community providers and families to help navigate the systems within their community for early identification and diagnosis.
- One rural community is working to develop their own diagnostic center.
- Directors of state diagnostic centers are doing talks in the rural communities to medical providers, school personnel and families on diagnosis and medical management of autism.



Benefits

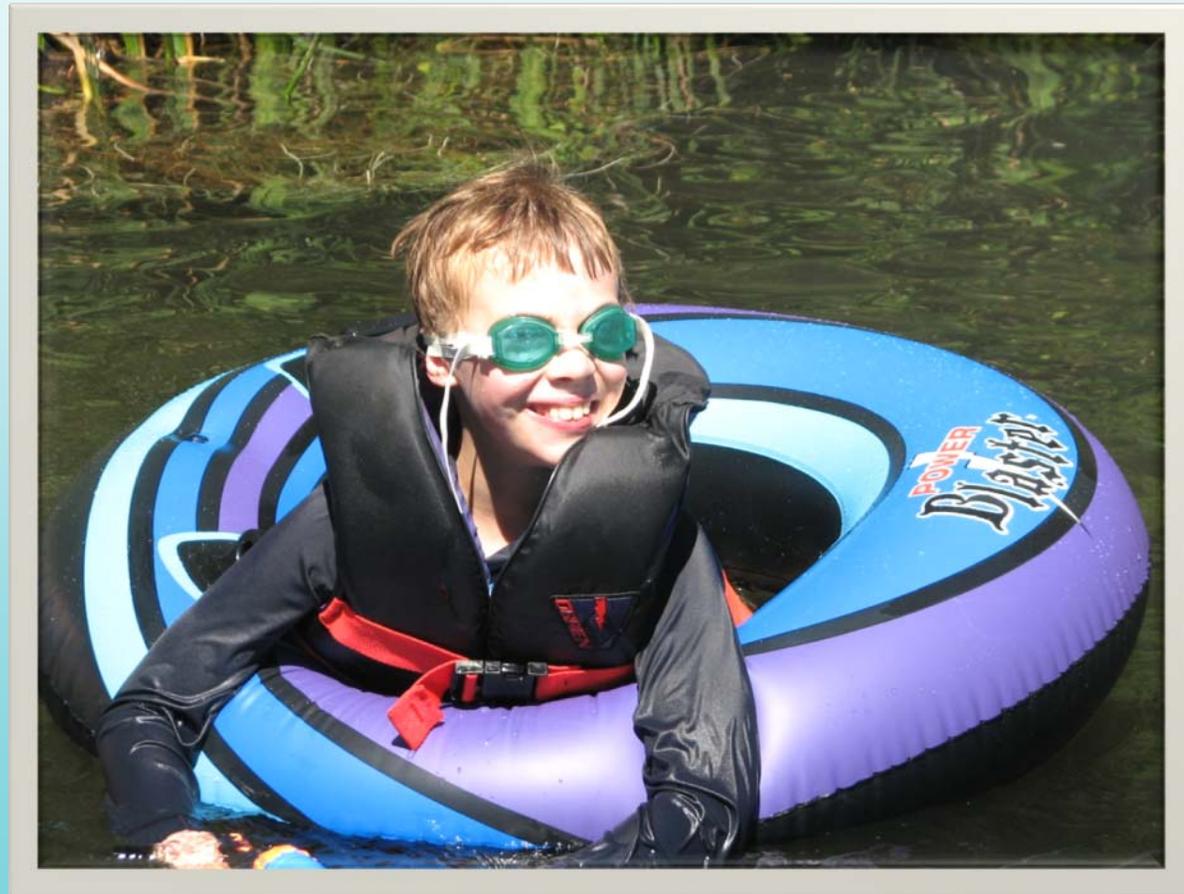
- The connection of local community medical providers with each other, to public health, and to developmental pediatricians at the diagnostic centers in the state.
- Bridging of the educational system to the medical system locally and state wide.
- The momentum is occurring in the communities to push this effort forward.



Projected Outcome

- The building of rural community infrastructure should increase the capacity to help ensure children with suspected developmental delays, like autism, get appropriate early identification and diagnosis in a coordinated, efficient, and timely manner.
- The building of rural community infrastructure will help families, schools, medical providers, and community members know how to access the services and resources for children with special needs in their community.

Why does it matter?



For More Information...

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**[WWW.DOH.WA.GOV/CFH/MCH/
Autism/Autism.htm](http://WWW.DOH.WA.GOV/CFH/MCH/Autism/Autism.htm)**



**University of
Washington
LEND Program**

Combating Autism Advisory Council



Questions and Answers

Thank you for attending this event. Please complete the evaluation directly following the webcast. An archives of this events will be posted (*<http://www.mchcom.com>*)