

A Survey of Washington State Neurodevelopmental Centers' Role in the Early Identification and Treatment of Autism Spectrum Disorders

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Combating Autism Advisory Council (CAAC)

- Combined effort of CSHCN and LEND under 2 grants awarded under Combating Autism Act of 2006
- September 2008 through August 2011
- Advisory body composed of members of previous Autism Task Force, autism experts, leaders, and individuals with ASD and their family members
- Activities include oversight to grant work, improve methods of information sharing, building partnerships, raise and spread Autism awareness
- LEND grant focus on training professionals for screening, evaluation, and treatment; expand training and research networks; policy development around prevention, treatment options, support services
- Access subcommittee initially examining availability of Multidisciplinary Diagnostic Teams

Survey Details

- 5 areas of questions: Screening, Assessment, Family Resources, Intervention for Child and Family, Professional Training
- Administered with Director or representative from each of 15 NDCs
- 20-30 minutes
- Telephone interview
- Sent questions in advance
- Participants invited to follow up with further information or questions

Screening

Summary

- 12 of 15 sites complete some screening
- 12 sites use M-CHAT
- Most use informal observations or self generated checklists
- Informal training for screening tools

Possible Direction

Consider recommendation for 1- 2 specific screening tools to promote consistency

Diagnostic Assessment

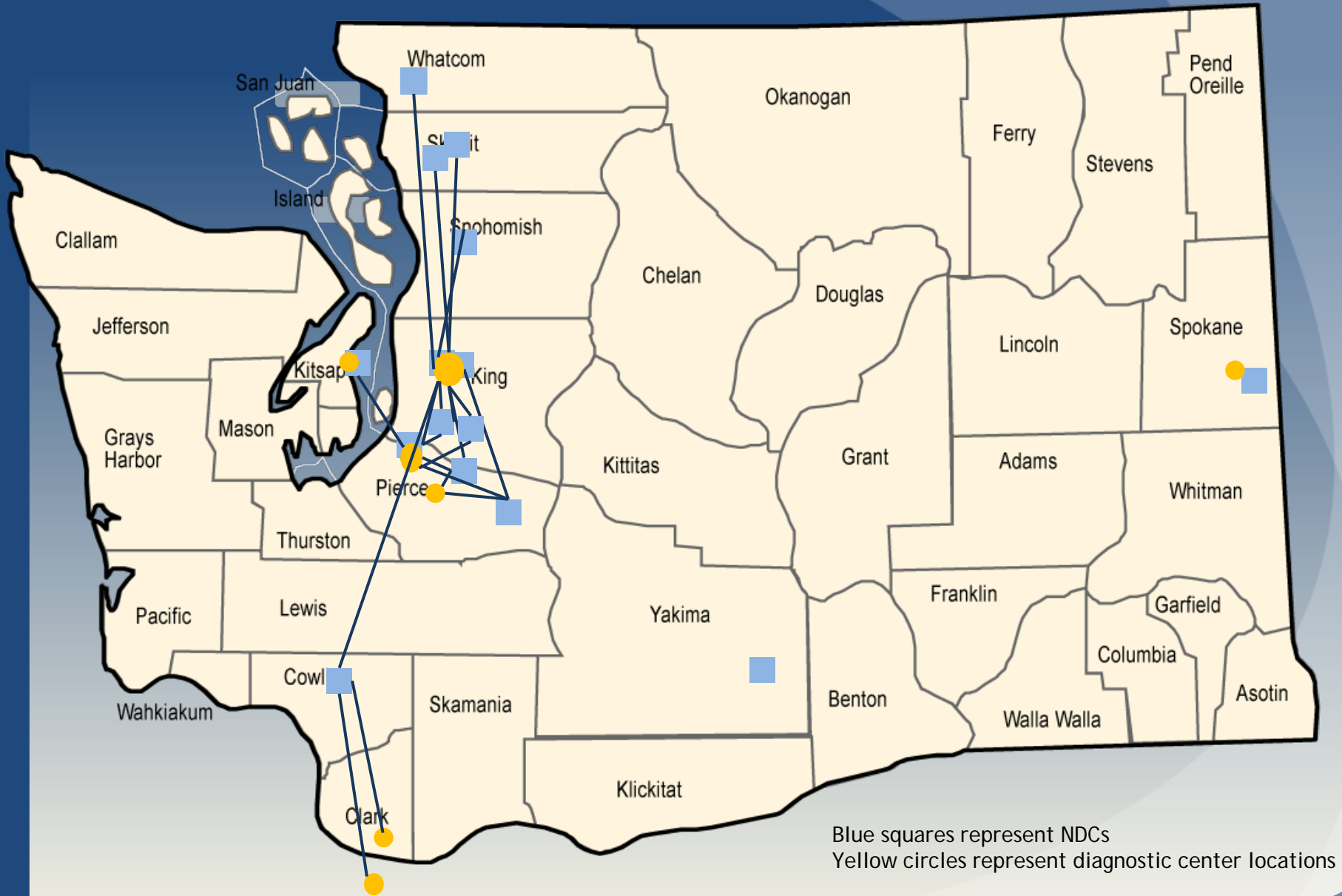
Summary

- All NDCs report some capacity to share (with diagnostic team) evaluation information from a variety of disciplines (OT, SLP, Education, etc)
- 5 NDCs report having more immediate resources for comprehensive evaluation through utilization of developmental pediatrician, psychologist, and/or neurologist

Possible Directions

- Consider identifying strong programs (collaborative and includes many disciplines) as model programs
- Develop template for NDCs and B-3 Centers to use in communicating observations and/or formal assessment data to PCP and diagnostic team

NDC Referral Patterns for ASD Evaluation



Blue squares represent NDCs
Yellow circles represent diagnostic center locations

Family Resources

Summary

- 14 of the sites have specific resources they provide families
- 9 of the sites do not think the resources are adequately meeting the needs of the families

Possible Directions

Identified needed resources fall into categories --

- Parent friendly: resources in other languages, Autism classes accessible to larger community, family to family contact
- Behavioral/Mental Health: direct support, parent support groups
- Institutional: time for service providers to gather and individualize materials, budget to support, quantity of books/DVDs
- Interventions: therapy availability and educational system information

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Intervention for Children and Their Families

Summary

- All NDCs offer specialized individual services and most also offer specialized classroom or group
- 8 centers offer support groups for families and caregivers, 6 centers offer family counseling

Possible Directions

- Need for -- up to date information about evidence based interventions; more mental health support; assistance with behavior management
- Consider opportunities for networked communication between early intervention providers from various centers

Professional Training

Summary

- 10 NDCs provide information or training to staff regarding identification of ASD related developmental red flags
- 14 interested in participation in addition training:
 - Evidence based intervention practices for children with ASD (14)
 - Discussing ASD concerns with family (12)
 - Strategies to work effectively with families effected by ASD (11)
 - ASD screening (9)
 - Referring for ASD diagnostic evaluation (7)
 - ASD assessment (7)

Professional Training

Possible Directions

- Other training requests: Early Start Denver Model; Project DATA; staying abreast of local resources; addressing cooperation skills needed in school in the clinic; behavior management within scope of professional practice; strategies for working in teams; collaboration with school district
- Consider needs of professional supporting families after ASD diagnosis:
 - Pacing of delivery of information
 - Increased time to organize and present information to families
 - Professional training focused on discussing concerns with families and strategies for working with families
 - Scope of practice issues
 - Mental Health support services and access: child, families, staff

Themes

- How to identify, share, and replicate successful models of service
- Coordination of resources for families: access, languages, timely, individualized
- Access to community based services: diagnostic, support, and treatment
- Need mechanisms for sharing information: technology, referral avenues, primary care providers

LEND core purpose

- Family-centered care, putting families and their concerns first
- Interdisciplinary care, building relationships among family, professionals, and community service providers
- Cultural competency, recognizing, respecting, and celebrating diversity
- Health and disability, promoting health and meaningful life participation for all children
- Leadership, developing trust and common vision with others to affect action and system change

Follow -Up

- How to identify, share, and replicate successful models of service
- Coordination of resources for families: access, languages, timely, individualized
- Access to community based services: diagnostic, support, and treatment
- Need mechanisms for sharing information: technology, referral avenues, primary care providers

Thank you

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