

Accessing Hard-to-Reach Communities: Innovative Projects by Act Early Teams Utilizing “Learn the Signs. Act Early.” Materials

**Learn the Signs. Act Early.
Quarterly Webinar Series**

June 29, 2011



Webinar Overview

- Introductions
- Presentations
 - **Bobbie J. Vaughn**, Florida Center for Inclusive Communities University of South Florida
 - **Kristine Green & Jimael Johnson**, State of Alaska - Division of Public Health
 - **Judith Holt**, Co-LEND Director, Utah Regional LEND, University Center for Excellence in Disabilities, Utah State University
- Q & A
 - Submit any questions throughout the webinar via the 'questions' box on your webinar dashboard. Moderators will read the questions following the presentations
- Survey

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Learn the Signs.
Act Early.



University Center of Excellence
for Developmental Disabilities

*Project Conectar: Building
the Capacity of a
Community to Learn the
Signs Act Early*

*Bobbie Vaughn, PhD
Training Director*



Project Conectar

- Research Topic of Interest (RTOI) about “Learn the Signs Act Early” (LTSAE)
- RTOI is a cooperative agreement between Association of University Centers on Disability (AUCD) and the Centers for Disease Control and Prevention (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD)
- Project Conectar proposes that using natural helpers or *promotoras* will assist Latino (Hispanic) families in Little Havana Miami to identify developmental delays in and access services for their children at an earlier age
- Project Conectar will evaluate CDC LTSAE materials, family needs for information, and access to services in an effort to impact through the intervention efforts of the *promotoras*, project staff, and collaborators



What are Promotoras ? How Do They Help?

- *Promotoras* is the Spanish word for Community Educator
- Provide culturally competent responsiveness to services
- Decrease barriers by acting as a conduit from families to providers
- Improve retention in services
- Provide health education
- Increase positive client outcomes, especially for Latino clients





Project Conectar Demographics

Mother

- Average Age: 31.2 (N=76)

- Age range: 17-44
- Level of Education: 31% less than HS (N=77)

Father

- Average age: 33.3 (N=66)
- Age range: 15-45
- Average Level of education: 27% less than HS (N=76)

■ Average length of time in the U.S.: 8.8 years (N=77)

■ Range: 2-32 years

■ Child (N=91)

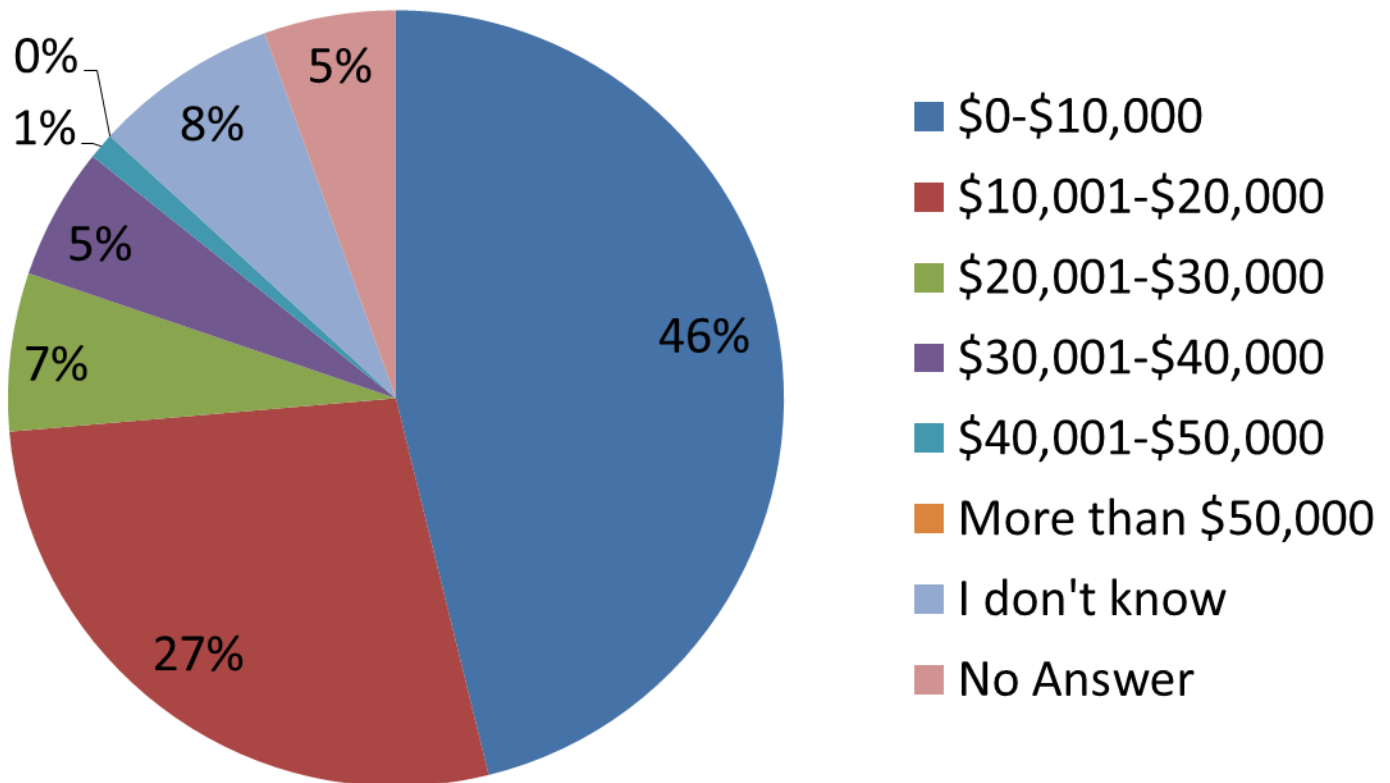
- Average Age (in months): 38.4 (*3 years, 2.4 months*)
- Age range (in months): 3-72 (*3 months-6 years*)
- *68% males, 30% female, 2% no answer*



Country of Origin	Mother & Father (N=156)
Honduras	40%
Nicaragua	17%
Peru	6%
Mexico	6%
Venezuela	5%
El Salvador	5%
Cuba	4%
Guatemala	4%
USA	3%
Argentina	3%
Colombia	3%
Dominican Republic	2%
Bolivia	1%
Ecuador	1%
Costa Rica	1%

Project Conectar Demographic Data

Household Income (N=78)





LTSAE Activities

- Establish advisory groups that consist of local providers (e.g., FDLRS, parent-to-parent, Part C providers, other relevant community agencies)
- Train neighborhood workers or grass roots/community agencies to administer developmental screenings
 - ASQ-SE
 - Family Service Assessment Survey
- Train to use Milestone Moments
 - Why use Milestone Moments
 - How to use Milestone Moments



LTSAE Activities cont.

- Screen in associated with neighborhood fairs or in neighborhood preschools
- Enlist LEND or UCEDD trainees in screenings as one of their activities
- Screen in connection with screening agencies to help reduce their screening wait list
- Create user-friendly, user-relevant materials through focus groups or meetings with families

Milestone Moments

You can follow your child's development by watching how he or she plays, learns, speaks, and acts. Look inside for milestones to watch for in your child and how you can help your child learn and grow.



2 Months

4 Months

6 Months

9 Months

1 Year

How **you** can help your child learn and grow

- Play on the floor with your baby every day.
- Learn to read your baby's moods. If he's happy, keep doing what you are doing. If he's upset, take a break and comfort your baby.
- Show your baby how to comfort herself when she's upset. She may suck on her fingers to self soothe.
- Use "reciprocal" play—when he smiles, you smile; when he makes sounds, you copy them.
- Repeat your child's sounds and say simple words with those sounds. For example, if your child says "bah," say "bottle" or "book."
- Read books to your child every day. Praise her when she babbles and "reads" too.
- When your baby looks at something, point to it and talk about it.
- When he drops a toy on the floor, pick it up and give it back. This game helps him learn cause and effect.
- Read colorful picture books to your baby.
- Point out new things to your baby and name them.
- Show your baby bright pictures in a magazine and name them.
- Hold your baby up while she sits or support her with pillows. Let her look around and give her toys to look at while she balances.
- Put your baby on his tummy or back and put toys just out of reach. Encourage him to roll over to reach the toys.
- When your baby looks at something, point to it and talk about it.

Your Baby at **9** Months



**What babies do at this age –
and how you can help their
development.**

*Talk with your child's doctor at every visit about the milestones
your child has reached and what to expect next.*

18 Months

2 Years

3 Years

9 Months

1 Year

What *children* do at this age...

3 YRS

Social/Emotional

- ☐ Copies adults and playmates
- ☐ Shows affection for playmates without prompting
- ☐ Takes turns in games
- ☐ Cares about others' feelings
- ☐ Understands the idea of "mine" and "his" or "hers"
- ☐ Shows a wide range of emotions
- ☐ Separates easily from mom and dad
- ☐ Gets upset with major changes in routine



Act early by talking to your child's doctor if your child:

- ☐ Falls down a lot or has trouble with stairs
- ☐ Drools or has very unclear speech
- ☐ Can't work simple toys (such as peg boards, simple puzzles, turning a handle)
- ☐ Doesn't understand simple instructions
- ☐ Doesn't speak in sentences
- ☐ Doesn't make eye contact
- ☐ Doesn't play pretend or make-believe
- ☐ Doesn't want to play with other children or with toys
- ☐ Loses skills he once had

Language/Communication

- ☐ Follows instructions with 2 or 3 steps
- ☐ Can name most familiar things
- ☐ Understands words like "in," "on," and "under"
- ☐ Says first name, age, and sex
- ☐ Names a friend
- ☐ Talks well enough for strangers to understand most of the time
- ☐ Says words like "I," "me," "we," and "you" and some plurals (cars, dogs, cats)
- ☐ Carries on a conversation using 2 to 3 sentences

Movement/Physical Development

- ☐ Climbs well
- ☐ Pedals a tricycle (3-wheel bike)
- ☐ Runs easily
- ☐ Walks up and down stairs, one foot on each step

Cognitive *(learning, thinking, problem-solving)*

- ☐ Can work toys with buttons, levers, and moving parts
- ☐ Plays make-believe with dolls, animals, and people
- ☐ Does puzzles with 3 or 4 pieces
- ☐ Understands what "two" means
- ☐ Copies a circle with pencil or crayon
- ☐ Turns book pages one at a time
- ☐ Builds towers of more than 6 blocks
- ☐ Screws and unscrews jar lids or turns door handle



How **you** can help your child learn and grow

- Go to play groups with your child or other places where there are other children, to encourage getting along with others.
- Work with your child to solve the problem when he is upset.
- Talk about your child's emotions. For example, say, "I can tell you feel mad because you threw the puzzle piece." Encourage your child to identify feelings in books.
- Set rules and limits for your child, and stick to them. If your child breaks a rule, give him a time out for 30 seconds in a chair or in his room. Praise your child for following the rules.
- Give your child instructions with 2 or 3 steps. For example, "Go to your room and get your shoes and coat."
- Read to your child every day. Ask your child to point to things in the pictures and repeat words after you.
- Give your child an "activity box" with paper, crayons, and coloring books. Color and draw lines and shapes with your child.
- Play matching games. Ask your child to find objects in books or around the house that are the same.
- Play counting games. Count body parts, stairs, and other things you use or see every day.
- Hold your child's hand going up and down stairs. When she can go up and down easily, encourage her to use the railing.
- Play outside with your child. Go to the park or hiking trail. Allow your child to play freely and without structured activities.

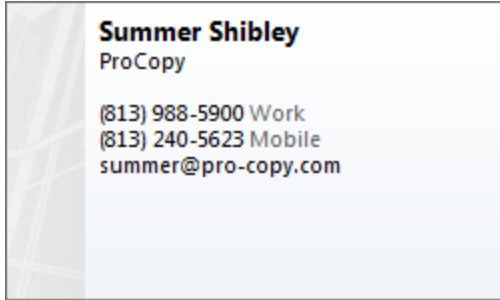
Questions for my Doctor



4 Months

9 Months



- Questions?
- Bobbie Vaughn
bvaughn@usf.edu
- For order info on Milestone Moments


Summer Shibley
ProCopy
(813) 988-5900 Work
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summer@pro-copy.com
- Or CDC
<http://www.cdc.gov/ncbddd/actearly/index.html>

State of Alaska, DHSS, DPH, Section of Women's Children's and Family Health

Learn the Signs / Act Early Campaign

Accessing Hard to Reach Communities: Alaska Peoples



Opportunity or Challenge?

The demographics of Alaska



- 1. Vast geographic service areas**
- 2. Small numbers of patients**
- 3. Multiple systems for care delivery**
- 4. Culture**
- 5. Expenses**
- 6. Limited workforce**

Pediatric Neurodevelopmental Outreach & Autism Screening Clinics

- 11 clinics
- 10 communities
- 21 clinical days



Traveling PND Clinic Objectives:

- ✓ Patient contact: Assessment, recommendation, and PN services
- ✓ Community outreach to providers
- ✓ Educational trainings for professionals and families
- ✓ Parent / Consumer meetings



✓ Southwest Alaska had a population of 53,349, less than 1/10 of Alaska's inhabitants. The population is in large part Alaska Native, with 58.1% identifying as entirely or partly "Native American."

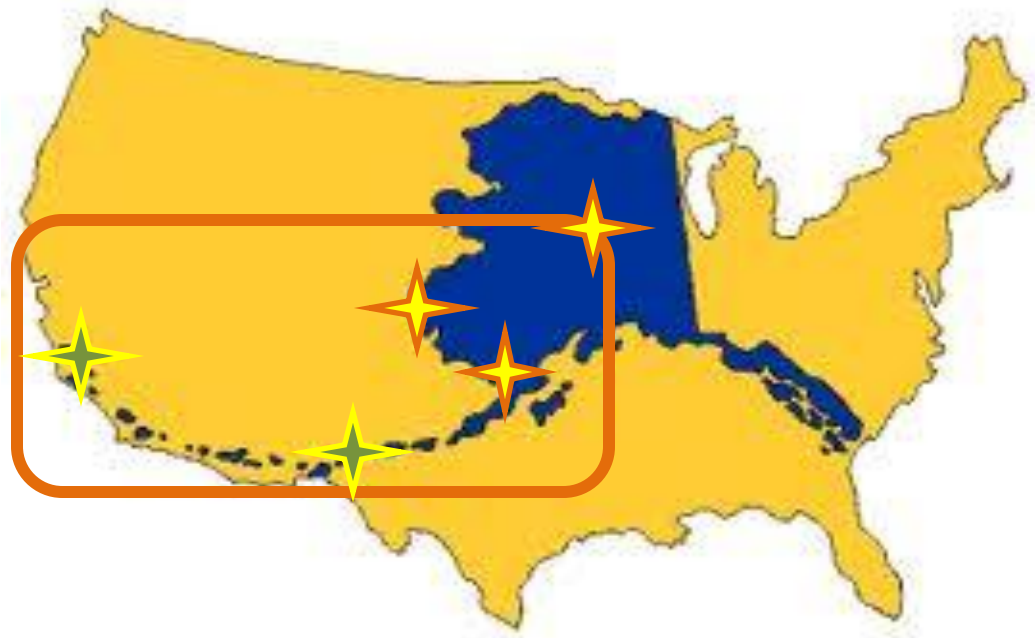
✓ About 121 towns and villages, generally far apart and with populations in the hundreds, exist in the region.

✓ The traditional Yup'ik Eskimo practices and language remain predominant in the area; subsistence activities and commercial fishing are significant activities in Dillingham and Kotzebue

✓ The Aleutian Islands with Adak and Unalaska are the largest towns, less than 4000 people with a total of 8000 living on the chain. Natives living on the chain are traditionally known as Aleuts

✓ Current population of PND Villages served is:

- ❑ Dillingham: 2264
- ❑ Bethel: 5803
- ❑ Dutch Harbor: 4376
- ❑ Attu Island: 20
- ❑ Fairbanks: 35,252



Alaska's Southwestern Region

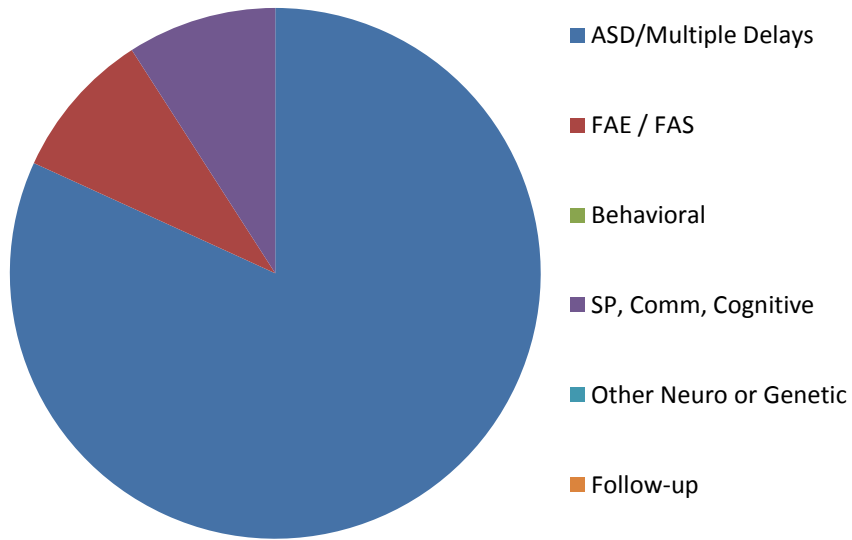
Alaska's Southwestern Region

PND Clinics Held In Dillingham & Bethel –
pts from entire region referred based on convenience for the family

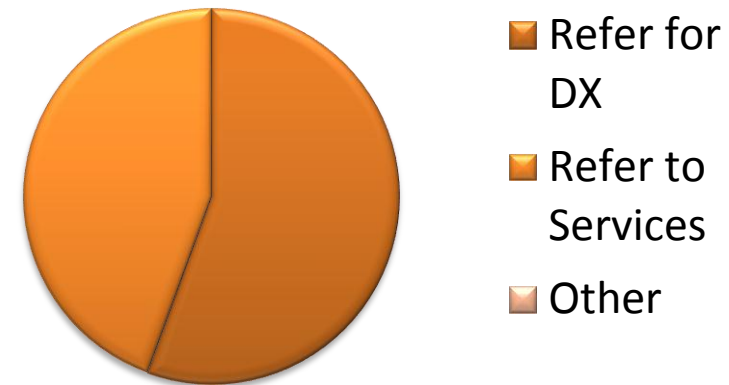


11 referrals ♦ 9 patients seen

Referral Concern (n=11)

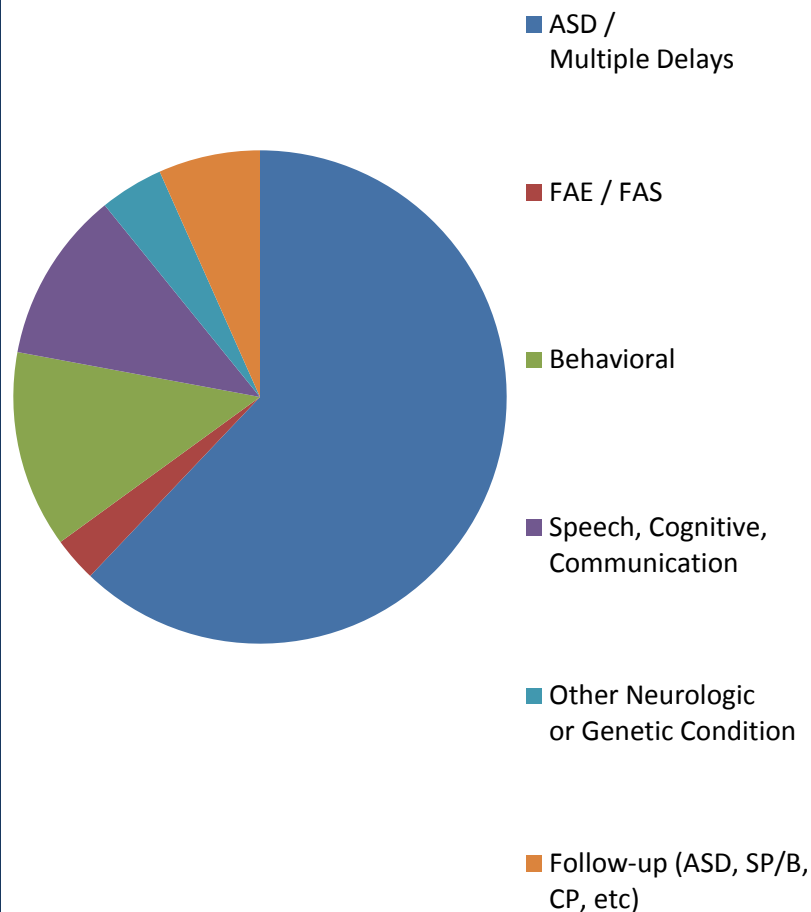


Recommendations (n= 9)



2010 Pediatric Neurodevelopmental Outreach and Autism Screening Clinic

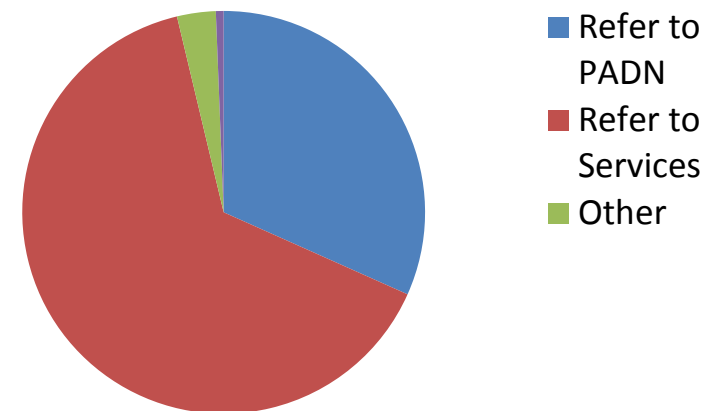
Referrals, Appointments, & Outcomes



•240 referrals / 161 pts seen

•68% of pts seen were scheduled for ASD R/O

• 32% of pts seen received recommendation for full-dx workup



Impact of Pediatric Outreach Clinics – Groundwork for Rural Alaska LTSAE Campaign

Campaign Implications

- Increased Cultural Sensitivity (ie written materials)
- Initial Campaign Material Exposure
- Network & Relationship Building

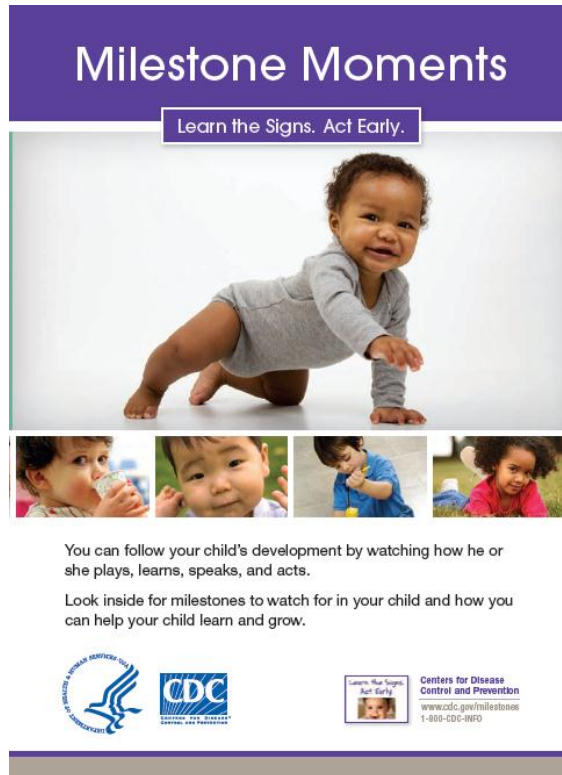


Partnership Opportunities

- Part C (Infant Learning) Programs
- Primary Care & Community Health Centers
- Early Childhood Collaboratives

Learn the Signs. Act Early

Alaska's Campaign



- Combating Autism & LTSAE Campaign
 - Review of campaign materials by focus groups and project partners
 - Some duplication of materials discovered
 - New CDC materials (specifically “Milestones Moments” Booklet) were very well received by audiences
- THE PLAN: Merge urban focused CDC Project with Part C statewide service delivery system rural focus...

Part C Partnership

Alaska's Infant Learning Program (ILP)



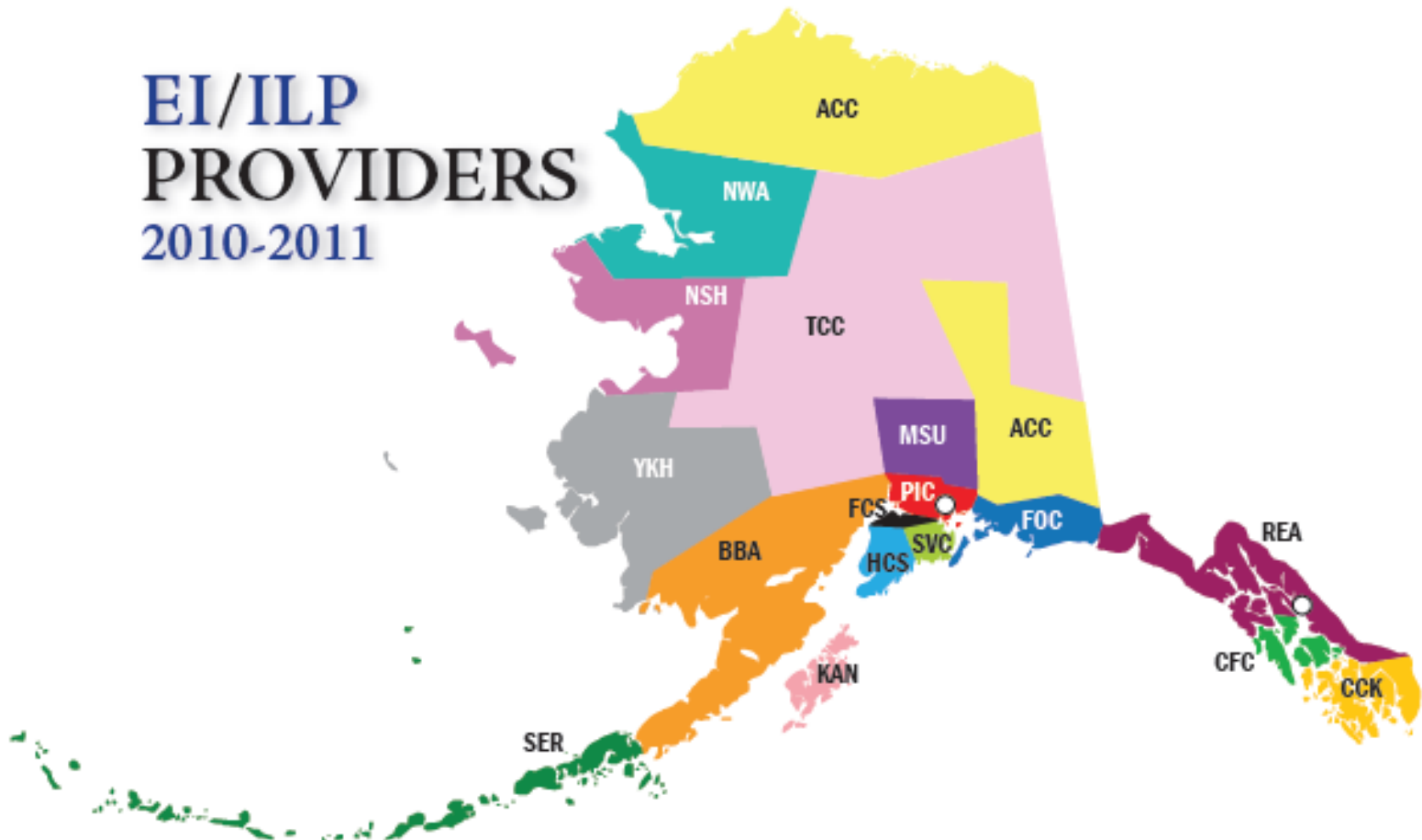
THE PLAN:

- Merge urban focused CDC project with Part C statewide service delivery system rural focus
 - Phase 1: Initial Direct Mailing
 - Packet of information including CDC LTSAE materials (i.e. “Milestones Moments” and complementary ILP literature)
 - Send to ALL Alaska parents of children ages 1-2 years
 - Use Vital Statistics birth records
 - CDC Target Population = Urban (Southcentral Alaska)
 - » ILP Target Population = Rural (Tribal Health, etc.)

Part C Partnership

ILP Regional Service Areas

**EI/ILP
PROVIDERS
2010-2011**



Part C Partnership

Alaska's Infant Learning Program (ILP)



– Phase 2: Data Collection & Analysis

- With CDC & ILP support, collect survey and qualitative data from families and providers to determine effectiveness of direct mailing
- Analyze and review results with ILP Coordinator

Part C Partnership

Alaska's Infant Learning Program (ILP)

- Phase 3: Sustainability through Ongoing Direct Mailings
 - Based on analysis of family/provider data and review of process, ILP and LTSAE Project staff will determine schedule and content of future mailings
 - ILP partnership offers sustainability through federally mandated structure and ongoing outreach efforts

DON'T WAIT.

Acting early can make a real difference!





Thank you!

Kris Green & Jimael Johnson

State of Alaska – Autism Program

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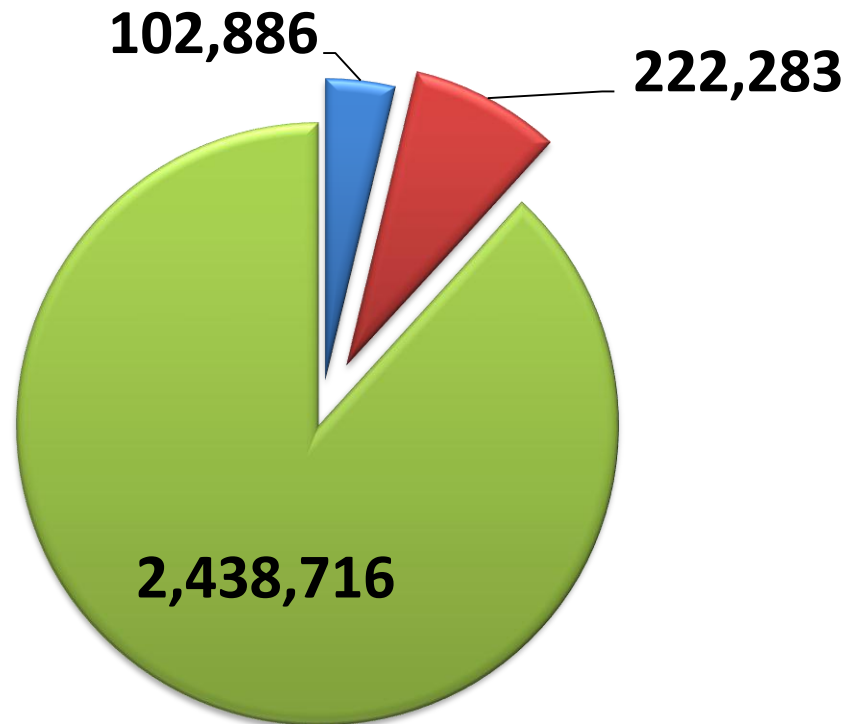
Serving Diverse Populations in Rural and Frontier Utah

Paul Carbone, MD
Judith M. Holt, PhD
Utah Act Early Team

2010 Census Data

Utah Residents

■ Frontier ■ Rural ■ Urban



The Challenge

- Develop a community based system of services for children with ASD that emphasizes:
 - The medical home as a headquarters for care
 - Timely surveillance and screening for ASD
 - Timely and comprehensive diagnostics
 - Assistance with ongoing care

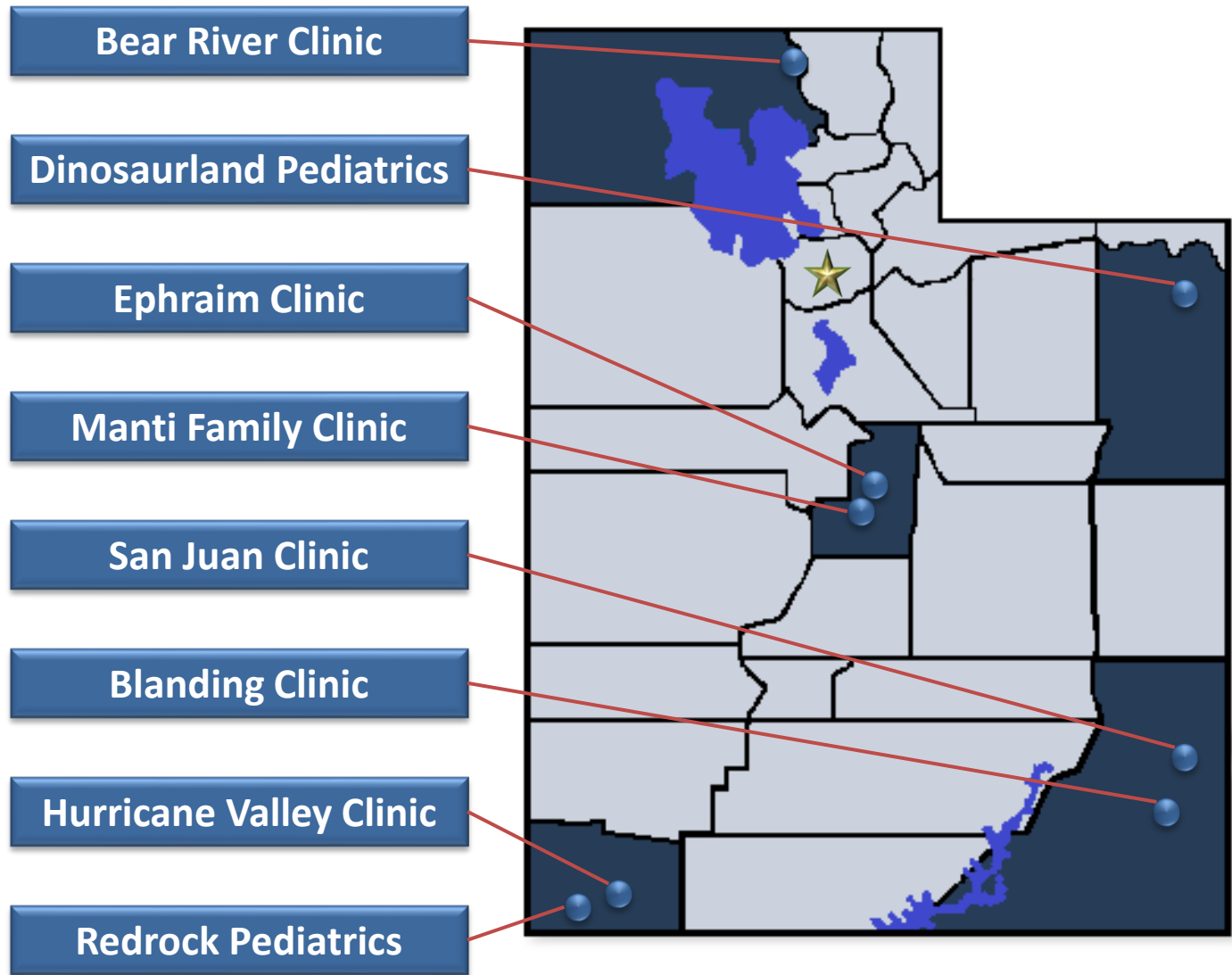
Early Autism Detection and Referral in the Medical Home



- 6-month learning collaborative
- Teams from 37 practices
- Learning session, monthly conference calls
- Goals: Implement universal autism screening at 18, 24 months
- Develop system for referral

OUTCOMES

- Improved surveillance and screening
- Better system of referral
- More family-centered care

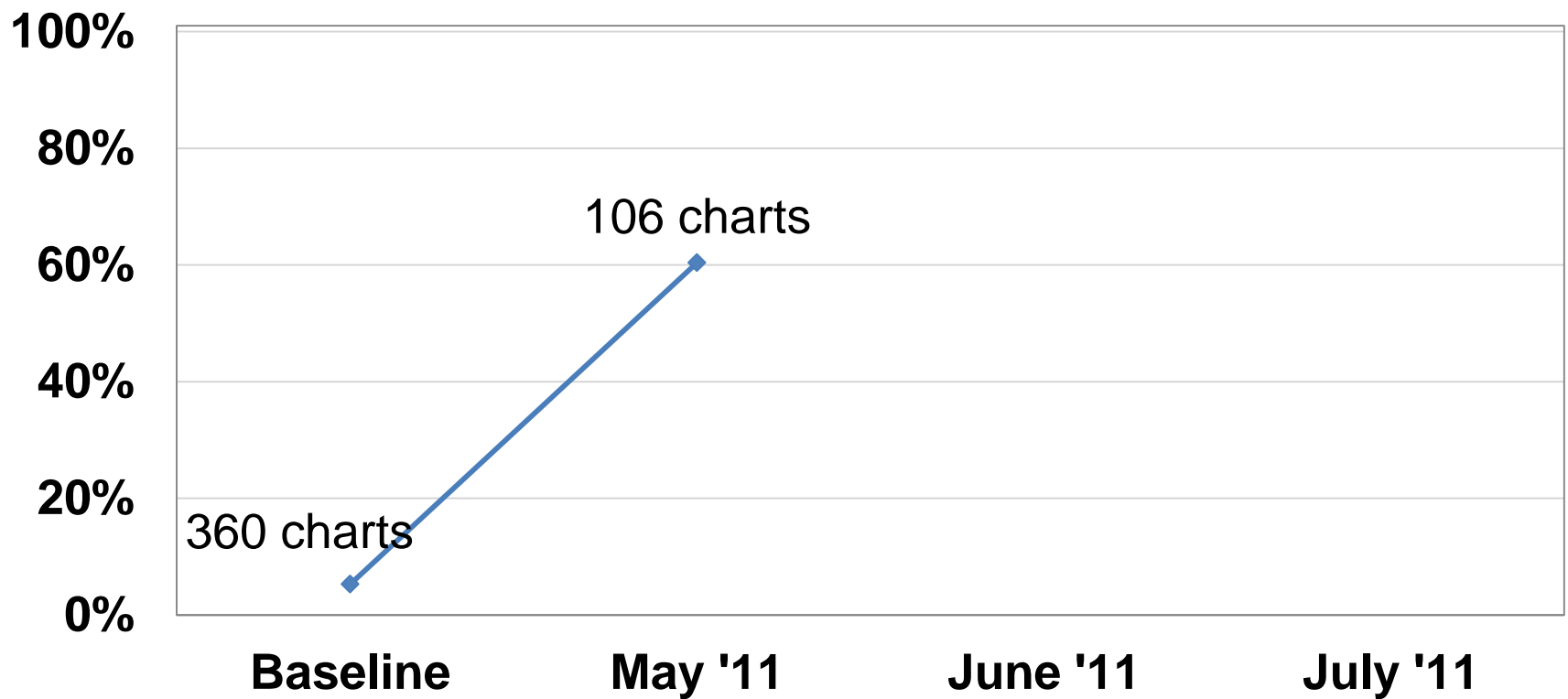


Early Autism Detection and Referral in Rural Utah

A UPIQ Learning Collaborative

- 3-month learning collaborative
- 3 web-based learning sessions
- Universal autism screening during 18- and 24-month visits—use of CDC materials in clinics
- Develop a registry of children with a suspected or confirmed autism diagnosis
- Implement a family-centered approach for children with special needs
- Learn quality improvement techniques

**Aggregate ASD Chart Audit Data:
M-CHAT performed during 18- or 24-month visit
Rural Utah
May 2011 - July 2011
8 Practices**



Utah Department of Health CSHCN Traveling Clinics

- Interdisciplinary team, eight sites
- Comprehensive assessment and case management
- Coordinate the delivery of services with the medical home and local agencies
- ASD: Diagnostic testing, treat associated conditions
- Blended state (DOH) and federal (Title V) funding



Lessons Learned...

- Interdisciplinary care can be delivered even in more rural locations with less resources
- Autism: Integrating the family, health care, and educational professionals creates success



ABCs of Autism

- Developed by URLEND faculty, trainees, and families
- Based on 12 hours of training across 6 weeks
- Experts in ASD
- First series presented in Salt Lake City
- Second series presented in Salt Lake City and videotaped

Statewide Availability

- Videotaped seminars transcribed
- Trainer's manual, clips of the video, and handouts developed
- Piloted initially with ASD Family Navigators
- Used widely in UT. Obtained additional funding to support it through 2011-2012.

ABCs of Autism for Spanish-Speaking Families

- Families and advocacy/support groups reviewed
- Prioritized modules
- Requested information that was less dense and had more discussion
- Added new module on screening and diagnosis
- Using CDC materials

Partnerships



Question & Answer

To ask a question:

- *Type your question into the 'question' box on your Webinar dashboard and the moderator will read it to the presenters

THANK YOU

Visit Our Websites

- *Learn the Signs. Act Early.” campaign
www.cdc.gov/actearly
- *AUCD’s Act Early Webpage www.aucd.org/actearly

Questions about the Webinar series?

- *Jennifer Bogin: jbogin@aucd.org
- *Cheryl Rhodes jgy6@cdc.gov

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