

**Building & Developing State Programs
to Identify and Improve the Health of
those affected by
Autism Spectrum Disorder and
Developmental Disabilities**

AMCHP Annual Conference - March 8, 2010

Presented by:

Grace Pushparany Williams – AMCHP

Bonnie Strickland – HRSA

**Kris Green, Jimael Lawson & Travis Hedwig – Alaska Autism Program
& George Jesien - AUCD**



State Public Health Coordinating Center for Autism

An Overview

Presented by:
Grace Pushparany Williams



State Public Health Coordinating Center for Autism

Primary Purpose

Increase the capacity of state Title V agencies to enhance services and supports to children, youth and families with ASD and other developmental disabilities

State Public Health Coordinating Center for Autism

Key Activities

- Create virtual State Public Health Autism Resource Center (SPHARC)
- Facilitate communication between State Demonstration Grantees
- Provide technical assistance to grantees and other public health agencies
- Collect Best Practices on Autism and Developmental disability service integration



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Drawing on the experiences and successes of states and partner organizations, the State Public Health Autism Resource Center (SPHARC) is a comprehensive resource center for state Title V agencies and others interested in improving systems for children, youth and families with Autism Spectrum Disorders and developmental disabilities. Visit SPHARC for state snapshots, promising practices, and other resources to support states as they develop and implement systems to improve the health and well-being of infants, children, and adolescents with autism and other special health care needs.

State Spotlight

Alaska



Alaska is the largest and most rural of the six demonstration grants. The state faces significant

Cultural Competency

States are currently working hard to develop culturally competent programs that raise awareness about ASD and engage newly diagnosed families from culturally, linguistically, and geographically diverse communities. Populations of specific concern to the State Demonstration Grantees include Hispanic, Native American, and rural families. Please see the materials below to learn more about current resources on this topic, an expanded definition of cultural competence, and what states are doing to advance culturally competent programs.

Partners and Resources

- [National Center for Cultural Competence](#)
- [Spanish and Other Non-English](#)

Upcoming Activities in Year 2

- Develop a public health policy framework
- Foster state peer to peer mentoring
- Collect best practices in select areas
- Continue topical technical assistance calls/webinars

State Public Health Coordinating Center for Autism

Common Technical Assistance Needs:

- Recruiting physicians (esp. family physicians) to participate in the medical home process
- Strategies to train providers (esp. in screening/diagnosis)
- Financing and reimbursement for autism services
- Involving families as partners
- Standards for care coordination
- Telehealth strategies to reach rural populations
- Transition issues for youth with ASD and DD

Healthy Children. Healthy Families. Healthy Communities.

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HRSA's Combating Autism Act Initiative (CAAI)

Bonnie Strickland, PhD
Director, Division of Services for
Children with Special Health Care Needs
HRSA/MCHB

Background

- Children with ASD fare significantly less well in the system than other Children with Special Health Care Needs (CSHCN),
- Findings from the National Survey of Children with Special Health Care Needs (NS-CSHCN) indicate that among CSHCN, children with ASD:
 - Had less access to important components of access, particularly those associated with more comprehensive care such as difficulty receiving referrals, family support services, or delaying care.

Background

- Were less likely to receive family-centered care.
- Their families were more impacted in terms of financial hardship, work and time spent coordinating care.
- Guidelines published by the American Academy of Pediatrics (AAP), recommended earlier and more frequent surveillance, and more aggressive management for ASD.

Systems Challenges

- Challenges:

- Earlier identification and intervention,
- Benefits in public and private insurance programs, financial planning,
- Transition planning, adult systems and services,
- Integration of ASD services into broader system,
- Inter-agency coordination.

Combating Autism Act

- NIH research into causes, diagnosis, early detection, intervention and treatment,
- CDC's Disabilities Surveillance and Research Program,
- HRSA to increase awareness, promote evidence based interventions, reduce barriers to screening & diagnosis, and train professionals to diagnose and provide evidence based interventions.

Program Overview

Address ASD and other developmental disabilities by:

- Increasing awareness;
- Reducing barriers to screening and diagnosis;
- Supporting research on evidence-based interventions;
- Promoting evidence-based guideline development;
- Training professionals to utilize valid screening tools to diagnose and to provide evidence based interventions.

Program in 4 Areas

Training

- Purpose

- Educate interdisciplinary health professionals,
- Provide continuing education and technical assistance to other providers,
- Contribute to building systems of services.

- Strategies

- Expansions and new Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs,
- Expansions to Developmental Behavioral Pediatrics training programs,
- National Interdisciplinary Training Resource Center (Association of University Centers on Disability (AUCD))

Program in 4 Areas

Research

- Purpose

- Utilize a network infrastructure as platforms to conduct research on evidence based practice for interventions Autism Intervention Research (AIR) Networks;
- Develop evidence- based guidelines and validate tools for interventions to improve health; and;
- Disseminate information on research, guidelines, and tools to health professionals and the public, especially families impacted by ASD and other DD.

- Strategies

- Physical Health—The General Hospital Corporation of Boston;
- Behavioral Health—University of California at Los Angeles.

Program in 4 Areas

State Demonstration

- Purpose

Promote Improved Systems of Services:

- Family/Professional Partnerships;
- Access to coordinated care through the medical home;
- Access to adequate health insurance and financing for needed services,
- Early and continuous screening and intervention,
- Community services organized for easy use, and
- Transition to adulthood.

- Strategies

- State Grants to implement statewide autism plans;
- State Public Health Coordinating Center (AMCHP).

State Demonstration Programs

Organization	City	State
Alaska Department of Health and Social Services	Anchorage	AK
The Hope School	Springfield	IL
The Curators of the University of Missouri/Thompson Center	Columbia	MO
Utah Department of Health	Salt Lake City	UT
Washington Department of Health	Olympia	WA
Wisconsin Department of Health and Family Services	Madison	WI
Rhode Island Department of Health	Providence	RI
University of New Mexico, Health Sciences Center	Albuquerque	NM
New York State Department of Health	Albany	NY

Program in 4 Areas

National Evaluation

- Purpose

- Monitor impact of program on access to care for children and youth with ASD and other DD;
- Required by the “Combating Autism Act of 2006”;
- Will be reported in HHS Secretary’s Report to Congress on progress related to ASD and other developmental disabilities.

- Strategies

- Logic Model and Research Questions for all program components;
- Collaboration with CDC and other Federal Agencies to determine collective impact.

Partnerships

- Working group with CDC to identify areas of collaboration and cooperation between HRSA and CDC on ASD related activities;
- Collaboration to propose a new HP2020 National Health Objective for early identification, diagnosis, and intervention for ASD;
- National Survey of Children with Special Health Care Needs (NS-CSHCN) and the National Survey of Children's Health (NSCH);

Partnerships

- Collaborate on Act Early Regional Summits in 10 Regions;
- Joint site visits for States with HRSA/CDC grants. And new IAA to enable CDC financial support to MCHB grantees to enhance CDC's Learn the Signs Act Early.
- Use HRSA State infrastructure to drill down to the State and local levels for public information campaigns;



Combating Autism

www.mchb.hrsa.gov/autism

This \$37 million effort, HRSA's implementation of the Combating Autism Act of 2006, addresses some of the most urgent issues affecting people with autism and their families. A national evaluation also will be conducted to report to Congress on progress related to Autism Spectrum Disorders and other developmental disabilities.

The evaluation will contribute to the U.S. Department of Health and Human Services Secretary's Report to Congress on progress related to Autism Spectrum Disorders and other developmental disabilities as required by the Combating Autism Act of 2006.

Funded Activities

- > [Training for Professionals](#)
- > [State Demonstrations and Policy](#)
- > [Autism Intervention Research Networks](#)
- > Increasing awareness;
- > Reducing barriers to screening and diagnosis;
- > Supporting research on evidence-based interventions for children and adolescents with Autism Spectrum Disorders or other developmental disabilities;
- > Promoting evidence-based guideline development for interventions; and
- > Training professionals to utilize valid screening tools to diagnose and to provide evidence based interventions.

Goal

Enable all infants, children and adolescents who have, or are at risk for developing, autism spectrum disorders and other developmental disabilities to reach their full potential by

- > **developing a system of services** that includes screening children early for possible Autism Spectrum Disorders and other developmental disorders;
- > **conducting early, interdisciplinary, evaluations** to confirm or rule out Autism Spectrum Disorders and other developmental disorders; and,
- > **providing evidence-based, early interventions** when a diagnosis is confirmed.



About Autism

- > [CDC: Autism Information Center](#)
- > [NICHD: Autism Spectrum Disorders](#)

Combating Autism Act

- > [Combating Autism Act: Public Law 109-416](#) (PDF, 49 KB)
- > [NIMH: Interagency Autism Coordinating Committee](#)
- > [IACC: Strategic Plan for Autism Spectrum Disorder Research](#)

Related Journal Articles

- > [A National Profile of the Health Care Experiences and Family Impact of Autism Spectrum Disorder Among Children in the United States, 2005-2006](#)

Contact

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Autism Program Development with Alaska's State Implementation Grant

AMCHP Annual Conference - March 8, 2010

State of Alaska – Division of Public Health:

Kristine Green, MAT, MS . Jimael Lawson, BA

with

Grace Pushparany Williams – AMCHP

Travis Hedwig, MA, PhD (c)

The Problem,

The rising numbers of children identified and diagnosed with Autism Spectrum disorders (ASD) and other developmental disabilities represent a challenge and opportunity for states. As a result, numerous state agencies including Title V, provider, and advocacy organizations are focused on developing and implementing systems to assure all children and youth with ASD receive early identification, assessment, diagnosis and intervention services.

Session Objectives

- Highlight Alaska's response to autism spectrum disorder (ASD) by fostering multi-disciplinary team development among state, tribal and local systems and refining systems of care .
- Provide useful examples of multi-disciplinary team development, work with community providers and systems, and develop culturally sensitive relationships with key stakeholders.

Working together to improve care for children affected with ASD



Families

Share Stories

We should do no program development nor federal legislation and policy making without investigating and prioritizing the family needs.

“Nothing About Us Without Us.”



States

Maintain objectivity

States build fair and equitable systems to serve all residents in need.



Federal

Policy and Initiatives

Campaigns and Initiatives need to be culturally sensitive and relevant to the recipients.

Using the Pyramid

to Build a System of Care

Faces of Autism

Grace Pushparany Williams (Parent) &
Travis Hedwig, Alaska Family Voices

A State's Response

Kris Green and Jimael Lawson – State of Alaska

Federal Initiatives

George Jesien - AUCD

Faces of Autism

- Grace Pushparany Williams: A parent's story



Family Voices



- Vision:
 - Every child and youth with special needs receives family-centered care.

Family Voices



- Mission:
 - Achieve family-centered care for all children and youth with special health care needs and/or disabilities
 - Through a national network, provide families with tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care

Family to Family Health Information Center



- **Primary Grant Objectives:**

- Promote family and professional partnerships.
- Assist families to make informed health care choices in order to improve health outcomes for CYSHCN.
- Promote the delivery of culturally responsive supports to families of children and youth with special health care needs.
- Support youth to successfully transition to adult health care, work and independence.
- Sustain the Family to Family Health Information Center program benefits to families across Alaska.

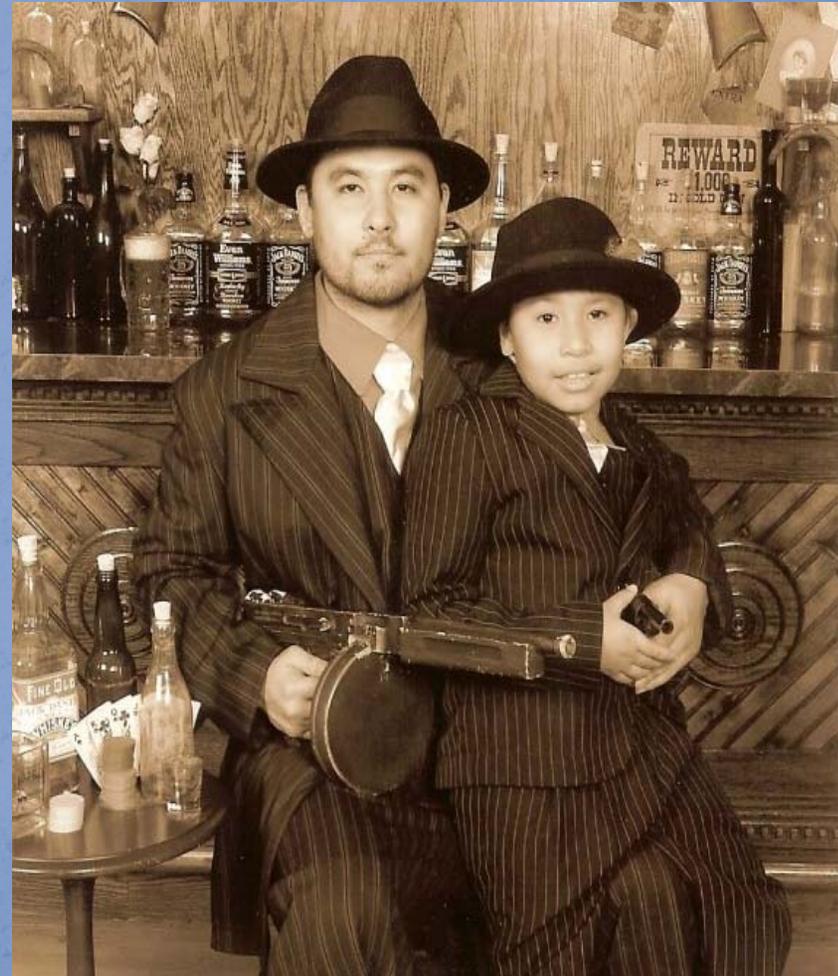
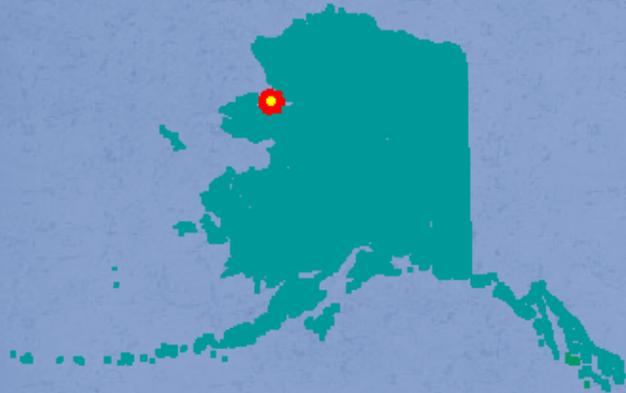
A Rural Alaskan Family's Story

- Meet a family from a remote Alaskan community....

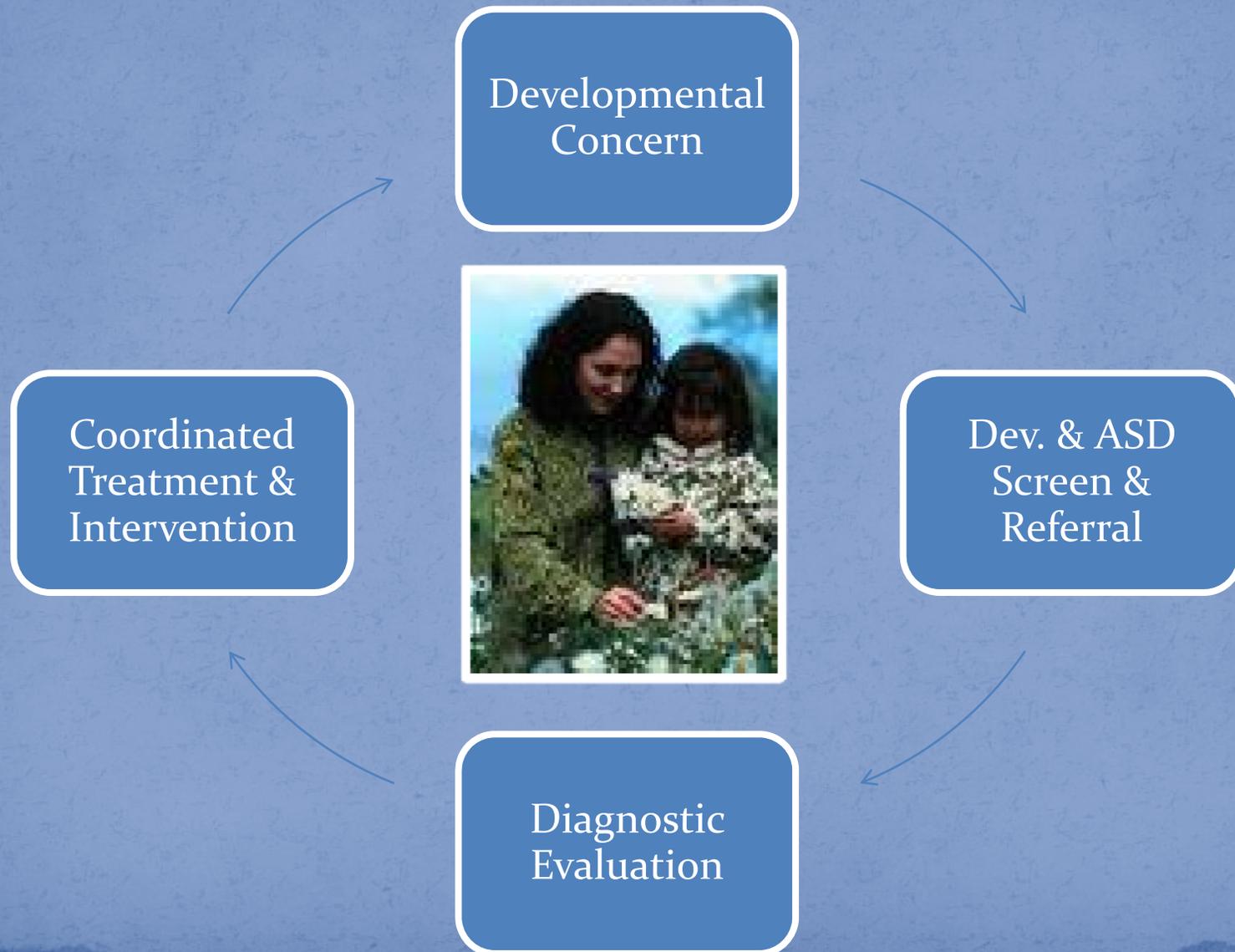


Anthony and Alika's Journey...

- From diagnosis to advocacy



Family-centered care delivery



**Governor's Council on Disabilities and Special Education
Autism Ad Hoc Committee**

Medical & Health

Screening & Intervention

Funding & Policy

Program & Infrastructure

How to meet the needs of
Alaska's children affected by
autism

Education & Training

Timely, Systematic, &
Evidence-Based

Family Support Srvs

Library, parent support, &
referral information

Governor's Council on Disabilities and Special Education 2006 State Autism Plan

- ❑ **Infrastructure building**: develop a strategic plan and find funding
- ❑ **Universal screening**: All Alaskan infants MCHAT screened at 18-month well-baby visit
- ❑ **Diagnostic clinic expansion**: comprehensive diagnostic medical services
- ❑ **Resources, referrals and training**: Public awareness, consultation services, and family support
- ❑ **Workforce training**: intensive academic training opportunities to prepare professionals to respond to Alaska's need
- ❑ **Time limited intensive early intervention** using successful evidence-based practice as platform



Combating Autism Act Initiative (CAAI) Alaska's State Implementation Grant

- **Goal One:** In rural Alaska, improve early detection, screening, intervention, and diagnosis for children with autism and other neurodevelopmental disorders.
- **Goal Two:** Increase number of children (ages 0-3) connected with Infant Learning Program (ILP/Part C) for services and a medical home.
- **Goal Three:** Align all these improvements with the State of Alaska Autism Plan and the Early Childhood Comprehensive Systems (ECCS) Plan.

Section of Women's Children & Family Health

Stephanie Birch, Section Chief

Thalia Wood, Assistant Section Chief

Children and Youth with Special Health Care Needs

Parent Services Mgr

Kris Green

Autism Staff

Jimael Lawson

CYSHCN

Parent Service
Development

Autism &
Neuro-
developmental
Outreach
Clinics

Contract/
Grant
Oversight

Title V

Federal
Combating Autism
Grant

Statewide Autism Partners and Stakeholders



Alaska Goldenheart Chapter
AUTISM SOCIETY
Improving the Lives of All Affected by Autism



University of Alaska Anchorage
Center for Human Development
A University Center for Excellence in Developmental Disabilities



Alaska Division of Public Health
Prevention Promotion Protection



Stone Soup GROUP
Supporting families who care for children with special needs



The TRUST
The Alaska Mental Health Trust Authority



ECCS
The Early Childhood Comprehensive Systems Initiative

- **Goal One:**
Improve early identification in rural Alaska

- 2009 Environmental Scan:

Medical
Providers

- Community Health Aides/Practitioners
- Public Health Nurses

Educational
Providers

- Infant Learning (Part C) Program
- Special Ed. Pre School

Head Start
& Childcare
Providers

- Head Start Programs
- Licensed Childcare Facilities

- **Goal One:**
Improve early identification in rural Alaska

Environmental Scan:

- Identified “Rapid Responder” provider groups and training needs
- Surveyed several provider & paraprofessional groups to determine best method of training delivery
- Followed up with qualitative “focus group” style data collection for more detail of regional needs

Conclusions:

- Some grant activities (i.e. In-home video screening) not appropriate at this time
- CHA/Ps require more basic child development training to use in general practice with young children for early detection
- EPSDT services (Early Periodic Screening, Diagnosis & Treatment) need to be streamlined with existing Part C and future screening initiatives

Alaska Tribal Health System: Community Health Aide Program

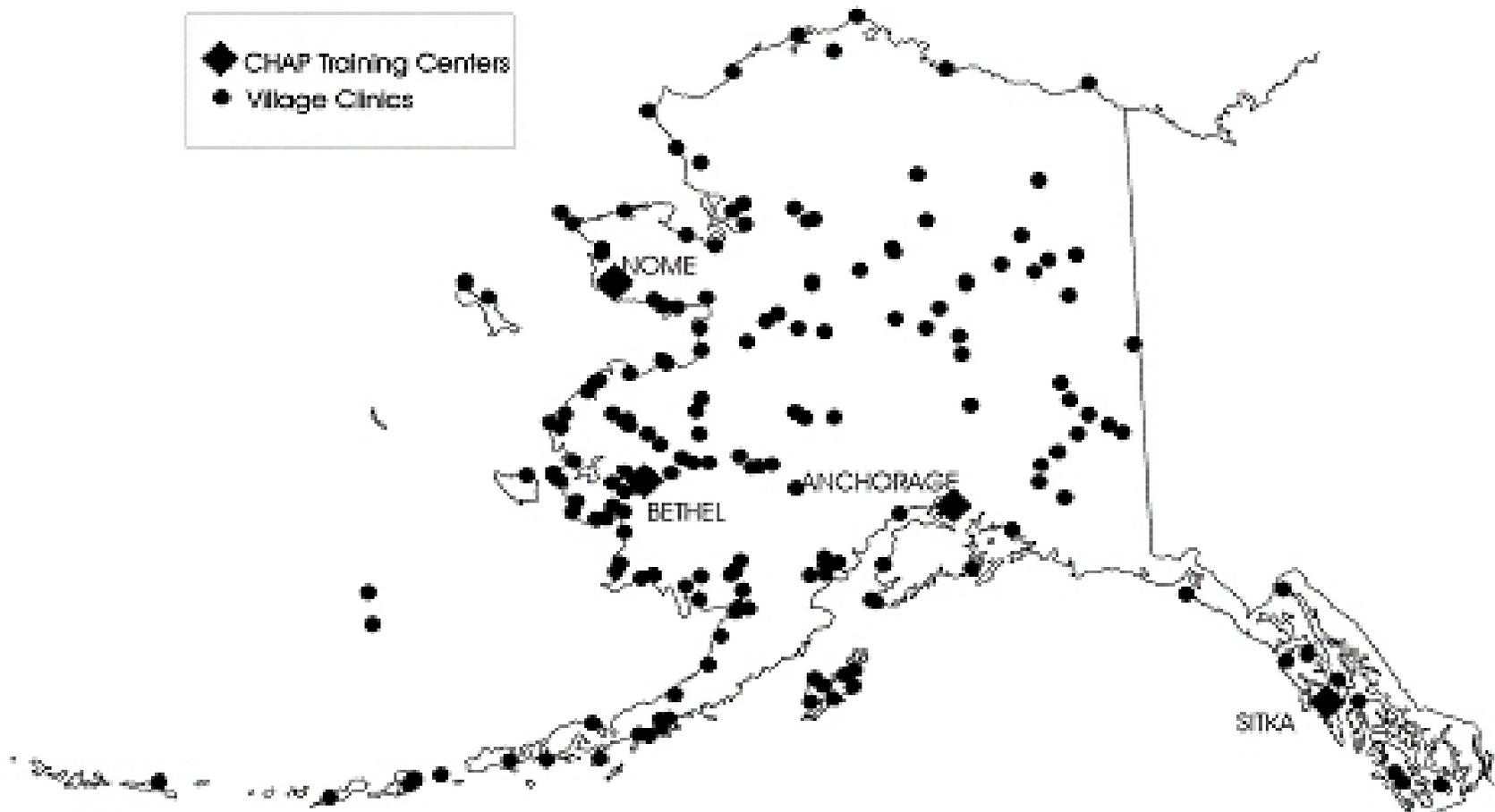
- Community Health Aides and Community Health Practitioners (CHA/Ps) are the first link to the ATHS for 60,000 Alaska Natives in 180 village clinics



- Approximately 300,000 encounters per year.
- Many children in their clinical practice.

Community Health Aide/Practitioner Village Clinics

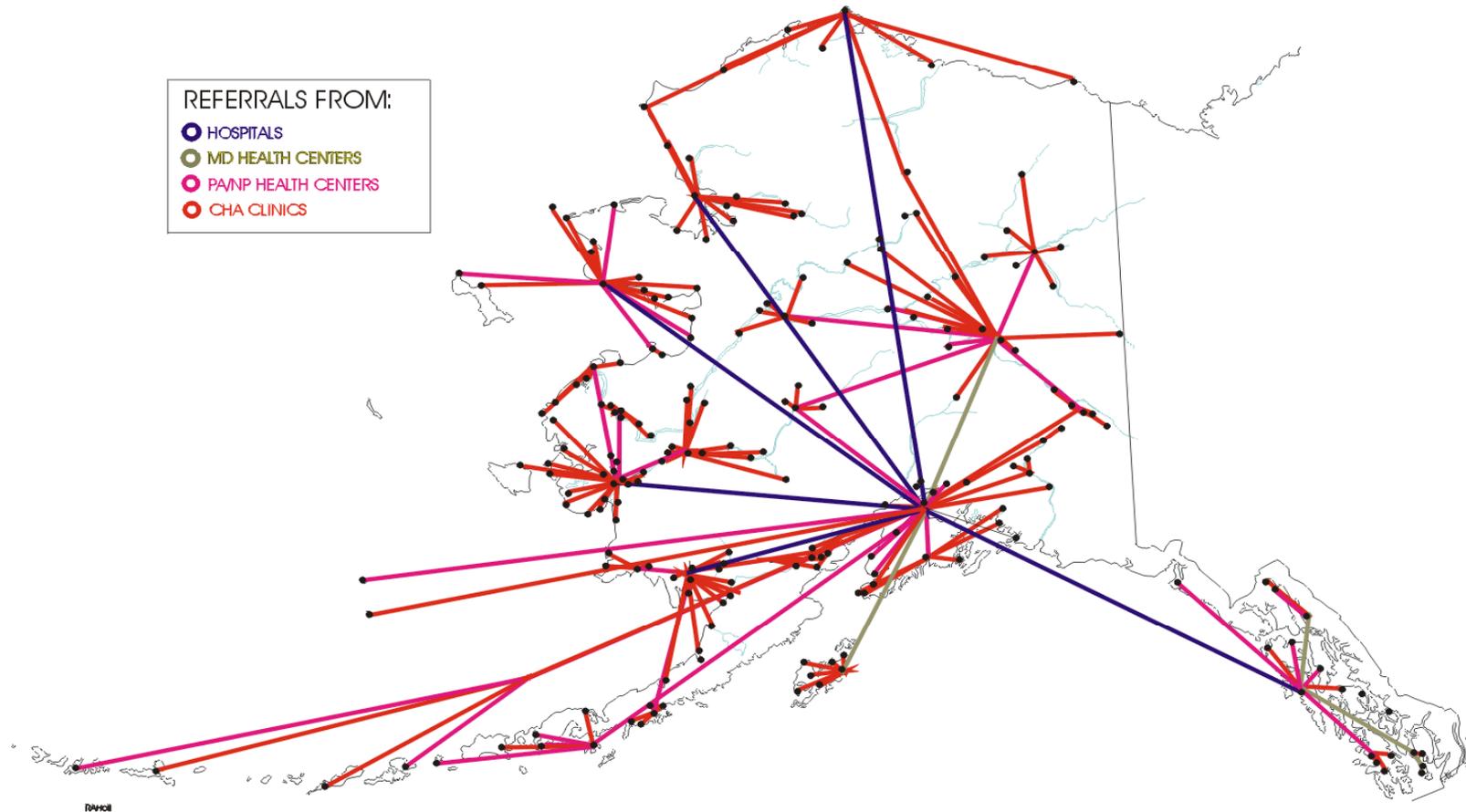
- ◆ CHAP Training Centers
- Village Clinics



THE ALASKA NATIVE HEALTH CARE SYSTEM

Typical Referral Patterns

- REFERRALS FROM:
- HOSPITALS
 - MD HEALTH CENTERS
 - PA/NP HEALTH CENTERS
 - CHA CLINICS



DW-01

Alaska Tribal Health System: Community Health Aide Program

- Collaborative Efforts with State Combating Autism Grant
 - Regional Trainings:
CHA/Ps to learn more about child development and case finding
 - Connect “Silo” Services:
Assist parents to better understand the health care delivery system



2010 Pediatric Neurodevelopmental & Autism Outreach Screening Clinics

Barrow
Kotzebue
Nome
Bethel
Dillingham
Kodiak
Fairbanks
Juneau
Ketchikan
Soldotna



Upcoming Activities with Rural Focus:

Public Awareness

- PSA (television and radio) for statewide distribution
 - *Featuring Anthony and Alika!*
- Adapt CDC “Learn the Signs – Act Early” materials to meet needs of rural health care providers

Training Initiatives

- Design and present regionally specific CHA/P trainings on ASD signs, screening and referral
- Distribute screening tools (ASQ-3, etc.) to providers
- Work with Part C (Infant Learning Program) to support hands-on skills training for rural health care providers

- **Goal Two:**
Connect children (ages 0-3) with ILP & Medical Home



- Distribute American Association of Pediatrics Autism Toolkits (total 250 statewide)
- Include ILP (Part C) program director and staff in all Early Intervention related planning
- Support Public Health Nurses and community “First Responders” with early identification materials and education (CDC and locally developed)

Multi-disciplinary Early Identification Efforts:

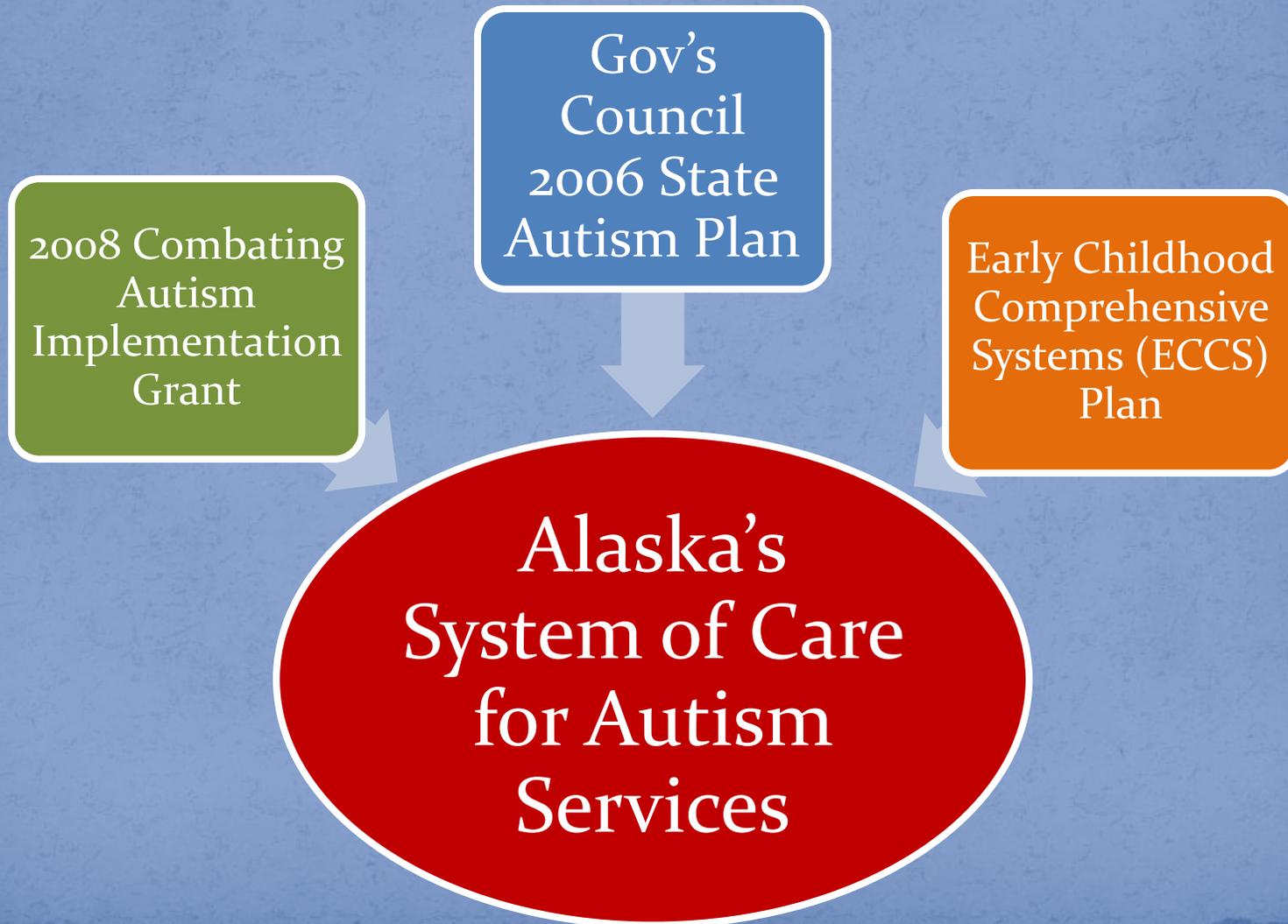
Public Awareness

- Promote collaborative training and informational sessions for parents and caregivers in multiple roles
 - *Foster Parents/Advocates*
 - *Homeschool Parents/Teachers, etc.*
- Create and maintain website with statewide and national resources for ASD identification and services

Training Initiatives

- Statewide Public Health Nursing M-CHAT (Modified Checklist for Autism in Toddlers) screening tool training
- Work with Part C (Infant Learning Program) to support hands-on skills training for rural health care providers

- **Goal Three:**
Align existing state plans and services for sustainability



February 2010: AUCD/CDC Region X “Act Early” Summit

Learn the Signs.
Act Early.



- Stakeholders brought together from each of four Region X states to discuss state autism planning
- Alaska & Washington both received CAAI State Implementation Grants in 2008

February 2010: AUCD/CDC Region X “Act Early” Summit 2006 State Plan Revisited

- Some original goals (i.e. Workforce Development) currently well addressed by multi agency & CAAI grant efforts
 - Board Certified Behavior Analyst curriculum
 - Undergraduate Tracks
 - Online and nationally recognized professional development opportunities



Continued efforts to align state systems:

- Region X Summit results:
 - Alaska's Region X summit stakeholders will reconvene in early 2010 to address the following:
 - Increase collaboration with Washington State LEND program
 - Define "Intensive Early Intervention Services"
 - Analyze funding systems to reduce service duplication and fill service gaps
 - Revise state plan, assign agency tasks – present to Governor's Council Autism Ad Hoc Committee for adoption and long term accountability

Continued efforts to align state systems:

- Additional Title V & CAAI Grant activities:
 - Offer structure and support to existing ECCS programs to improve early universal screening
 - Explore autism surveillance opportunities
 - Support University research initiatives to reduce cultural barriers to early identification & svcs
 - Coordinate Tele-health systems to improve health care access (rural focus)

The future of Alaska autism service development: Transitions throughout the Lifespan



- Cultural Sensitivity:
 - When urban meets rural...
- “Bring the Kids Home” Initiative
- Lifespan transition issues
 - *ILP to Preschool*
 - *High School to Workforce, etc.*

Home with a treatment and intervention plan
.....is good for everyone



Thank you

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Act Early Regional Summits, A Collaborative Effort¹

AMCHP Conference
March 8, 2010

George Jesien, Ph.D.
Association of University Centers on Disabilities,
AUCD

1. Slides adapted from G. Peacock, MD, MPH, 2010



Learn the Signs. Act Early.

Learn the Signs.
Act Early.



www.cdc.gov/actearly

Learn the Signs. Act Early.

- Traditional health communication campaign
- Capacity building through the Act Early project
- Partnership engagement
- Evaluation



Communication Objectives

- Raise *awareness* of developmental milestones and early warning signs of developmental delay.
- Increase *knowledge* about the benefits of early action and early intervention.
- Increase parent-provider *dialogue* on the topic of developmental milestones and disorders.
- Increase *early action* for developmental disorders.



Target Audiences

- Health Care Professionals
 - Pediatricians, family physicians, physician assistants, nurses, allied health professionals
- Parents of Young Children
 - Ages 4 and younger
- Early Educators

Working Together



Maternal & Child
Health Bureau



National Center on
Birth Defects &
Developmental
Disabilities



UCEDD/LEND
Centers & Programs

Capacity building

- Act Early Summits
- Act Early Minigrants
- Research Topics of Interest (RTOIs)
- Collaborative Research Awards (CRAs)

Act Early Summits



Improving system collaboration & effectiveness

When we started...

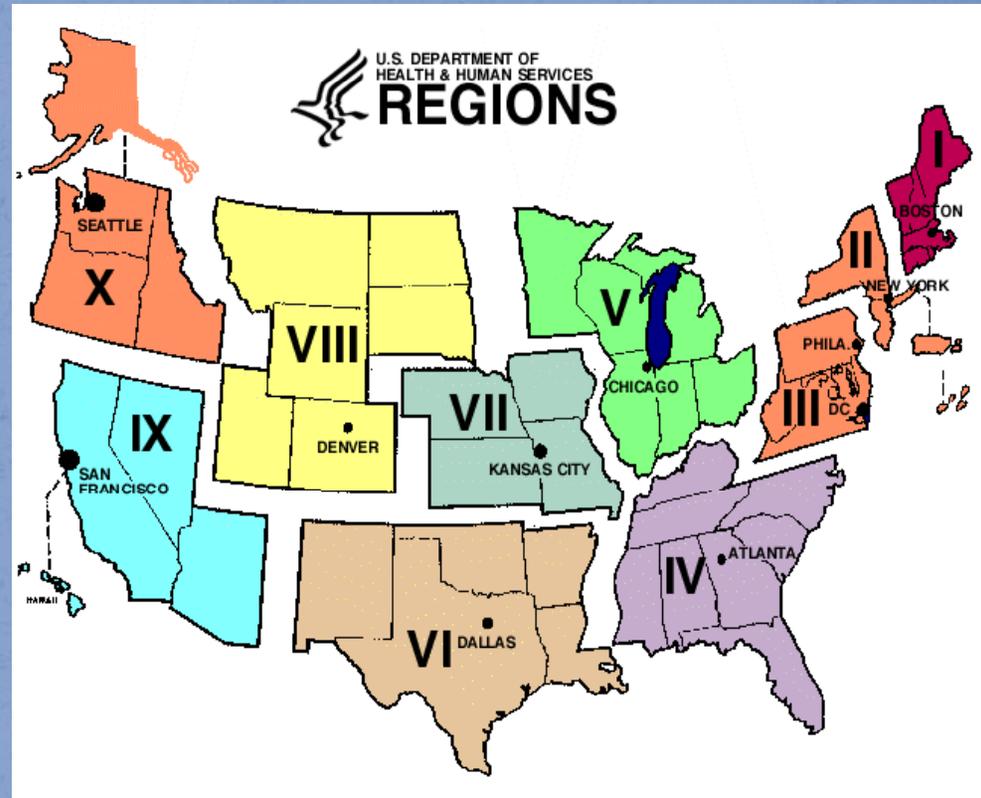
Objectives of the Act Early Regional Summits

- Increase awareness of the “Learn the Signs. Act Early.” campaign and its impact in target regions
- Develop common understanding among stakeholders of opportunities, challenges and barriers to early identification and diagnosis
- Develop state plans to enhance state wide early identification, diagnosis and service provision and coordination for families with ASD



Regional Summits

- 2007
 - Chicago, IL
- 2008
 - Kansas City, MO
 - Albuquerque, NM
- 2009
 - Nashville, TN
 - Salt Lake City, UT
 - The Bronx, NY
 - Sacramento, CA
 - Atlanta, GA
- 2010
 - Seattle, WA
 - Philadelphia, PA
 - Providence, RI



State teams formulation: Regional Summit Invited Stakeholders

- Part C Early Intervention Program
- Preschool Special Education – Section 619 of IDEA
- Title V - Children with Special Health Care Needs
- Developmental Disabilities Services Office
- State Public Health
- Child Care Resource and Referral
- Foster Care Bureau
- Head Start and Early Head Start
- Developmental Disabilities Council
- American Academy of Pediatrics State Chapter Representative
- UCEDD/LEND Representative
- Autism Organizations–Autism Society of America, Autism Speaks, Easter Seals, NATTAP, etc.
- Parent Organizations–Parent Training Center, Family Support, or Parent Health Information Center
- State Medicaid and Health Insurance
- Legislature- member or staff

Production of a State Plan

- Bring key stakeholders in early Identification and intervention together
- Pre-work occurs on the logic model
- Sharing on the “State of the State”
- Continued work on logic model
- Creation and presentation of a state plan

Identified Gaps and Challenges

- Few well trained professionals
- Disparities among population groups
- Lack of services
- Use of non evidence based services
- Funding



Proposed Outcomes

- Increased public awareness about ASDs and other DDs
- Seamless transition among service systems
- Statewide training for families and practitioners
- Address disparities to increase services for underserved

Proposed High-Priority Activities

- Increase public awareness about the importance of early intervention
 - Work with key stakeholders to increase outreach
 - Disseminate information such as Learn the Signs. Act Early materials



Proposed High-Priority Activities



- Create a statewide technical assistance network
 - Increase interdisciplinary training
 - Develop effective, evidence based interventions and model approaches

Act Early Minigrants

- Continue to enhance awareness and coordination of early identification and early intervention service systems for children with ASD and their families
- Provide catalyst to support ongoing collaboration of state team members
- Further activities developed in the state plan and initiated by state teams as a result of the Regional Summits

State teams



- Continuing to meet
- Expanding membership of team
- Collaborating with others

Other Outcomes



- Legislative advocacy
 - Raising awareness of policy makers about autism and Act Early messages
- Better coordination across systems
- Activities focused on rural, underserved populations
- Creative training of professionals

Newly funded Act Early projects Inspired by the summits

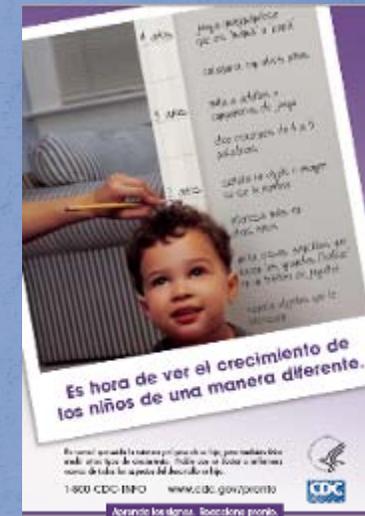
Funded RTOIs



- Parent detailers in primary care practices (GA State)
- Reaching Hispanic families to *Learn the Signs and Act Early* (Univ of S. Florida)
- Reaching parents at risk for entering the child welfare system (GA State)

Future directions

- Work closely with HRSA state demonstration programs on awareness
- Fund further state planning
- Future summits
- Policy workshop



Future directions

- Clarifying benchmarks for measuring identification, assessment and diagnosis
- Parents' knowledge, attitudes and beliefs around early action
- Continuing to reach hard-to-reach populations



Conclusion

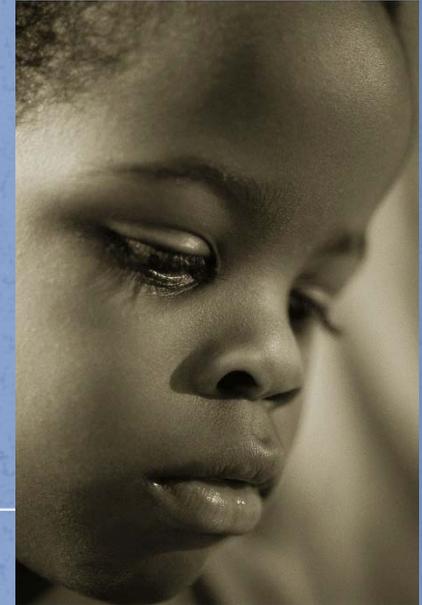
- Summits have provided a forum to improve system collaboration
- Informed future directions for CDC's awareness and Act Early activities
- Created the opportunity for synergy between HRSA, CDC, AUCD & AMCHP





Questions?

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Thank You!