AUTISM & FASD THE GOVERNORS COUNCIL ON DISABILITIES AND SPECIAL EDUCATION



TITLE V MATERNAL CHILD HEALTH PROGRAM

- Three major child health concerns were identified by those raising children with a special health care need:
 - Behavioral/mental health challenges
 - Social isolation
 - Bullying

WHAT THE COUNCIL DID

- Conducted forums in 15 communities statewide
- Heard over and over about need for diagnosis and services
 - Gaps in screening and diagnosis
 - Early intervention and education
 - Child care
 - The "cliff" of adult services
 - Where does FASD "live"?

DISPARITIES

- Alaska experiences significant disparities in screening evaluation and diagnosis
 - Referrals
 - Inconsistent screening and screening tools
 - Inconsistent clinic locations and days
 - Geographic distribution and scope of generalists and subspecialists
 - Developmental-behavioral pediatricians, and other specialists

LIMITED ACCESS

- Evidence based practices,
 - Appropriate education,
 - Supports and accommodations,
 - Professional training,
 - Insurance and Medicaid program coverage,
 - Employment and housing,
 - Community engagement and family and caregiver supports

PREVALENCE

American Academy of Pediatrics – FASD: Perspectives on Prevalence

Birth Defect	<u>Prevalence</u>
Down syndrome	1.2/1000 births
Cleft lip =/-palate	1.2/1000 births
Spina bifida	1/1000 births
Autism	12.5-14/1000*
Fetal Alcohol Syndrome (FAS)	6-9/1000*
ALL FASDs	24-48/1000*

^{*}per 1000 school age children

FASD

- High prevalence
- Referrals and screening tools
- Foster care system
- Screening and Diagnosis
- System? Which system
- Education evaluation
 - Other Health Impairment Regulation

AUTISM

- Screening
- Evaluation and diagnosis
- Education
- Behavior
- Applied Behavior Analysis and insurance/Medicaid
- Post secondary transition
- The "Tsunami" of autism



Despite these challenges, Alaska's medical and mental health community and families are highly motivated to improve the current system of diagnoses, support and care through integration, partnerships and greater collaboration.

SHORT LIST OF PARTNERS

- Women's Children's and Family Health
- Tribal health
- Behavioral health
- Senior and disability Services
- Early intervention
- Education
- Division of Vocational Rehabilitation
- Providers
- Medicaid

- Help Me Grow
- Children and Youth With Special Health Care Needs
- Early childhood comprehensive Systems grant
- The Mental Health Trust
- FASD Partnership
- Private and nonprofit clinics
- Parent support groups

WHAT WE NEED

- Greater access to screening and diagnosis
- Specialists
- Expanded use of Telepractice
- Sustainable resources that include insurance and Medicaid/CHIPS/EPSDT and family and caregiver supports
- Comprehensive and collaborative planning

WHAT ELSE WE NEED

- Workforce development and training for:
 - medical and behavioral health providers
 - educators
 - employers
 - legal system
 - families
 - o public

THE COUNCIL'S COMMITMENT

- Autism Ad Hoc Committee
- FASD Workgroup
- Targeted disparity focus
- Across the lifespan
- Offer ourselves as a resource

QUESTIONS?

