Alaska FASD Facts & Figures

Prepared by
Alaska Mental Health Board and
Advisory Board on Alcoholism
and Drug Abuse

for the

Alaska FASD Partnership

What is FASD?

- *Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual who was prenatally exposed to alcohol.*
- *These effects may include physical, mental, behavioral and/or learning disabilities, with lifelong implications.*
- *FASD is NOT a diagnostic term ... but refers to specific conditions, such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD).*

Source: *"Fetal Alcohol Spectrum Disorders by the Numbers," U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA), 2006.*

What is FAS?

Only Fetal Alcohol Syndrome (FAS) has diagnostic guidelines. A diagnosis of FAS has three major components:

- *distinctive facial features*
- *growth deficiencies*
- *brain damage*

Behavioral or cognitive problems may include intellectual and learning disabilities, attention deficits, hyperactivity, poor impulse control, and social, language, and memory deficits.

Source: *"Fetal Alcohol Spectrum Disorders by the Numbers," U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA), 2006.*

What is ARND and ARBD?

Alcohol-Related Neurodevelopmental Disorder (ARND) and Alcohol-Related Birth Defects (ARBD) describe cases in which individuals were prenatally exposed to alcohol, and have some, but not all, the signs of FAS.

- *ARND refers to neurologic abnormalities*
- *ARBD describes defects in the skeletal and major organ systems*

Individuals with ARND and ARBD do not have the distinctive FAS facial features.

Source: *"Fetal Alcohol Spectrum Disorders by the Numbers," U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA), 2006.*

How does alcohol cause damage to the developing fetus' brain?

- *Alcohol is a teratogen – a substance that causes abnormal development in a fetus*
- *Alcohol passes into to the fetus' bloodstream through the placenta*
- *Alcohol dissolves cells, causing damage to the developing fetus*
- *Since the brain and central nervous system are developing throughout the entire pregnancy, the fetus' brain is always vulnerable to damage from alcohol exposure*
- *The areas of the brain that are affected depend on which areas were developing at the time of alcohol consumption*

There is no KNOWN amount of alcohol that can pass safely through the placenta without causing damage

Regions of the brain commonly affected by prenatal alcohol exposure

- ***Prefrontal Cortex***– *controls impulses and judgment*
- ***Corpus Callosum*** – *passes information from left hemisphere (rules, logic) to right hemisphere (impulses, feelings). Can influence attention, psycho-social and verbal learning*
- ***Basal Ganglia*** – *cognitive functioning, spatial memory, perception of time*
- ***Cerebellum*** – *balance, coordination, learning and cognitive skills*

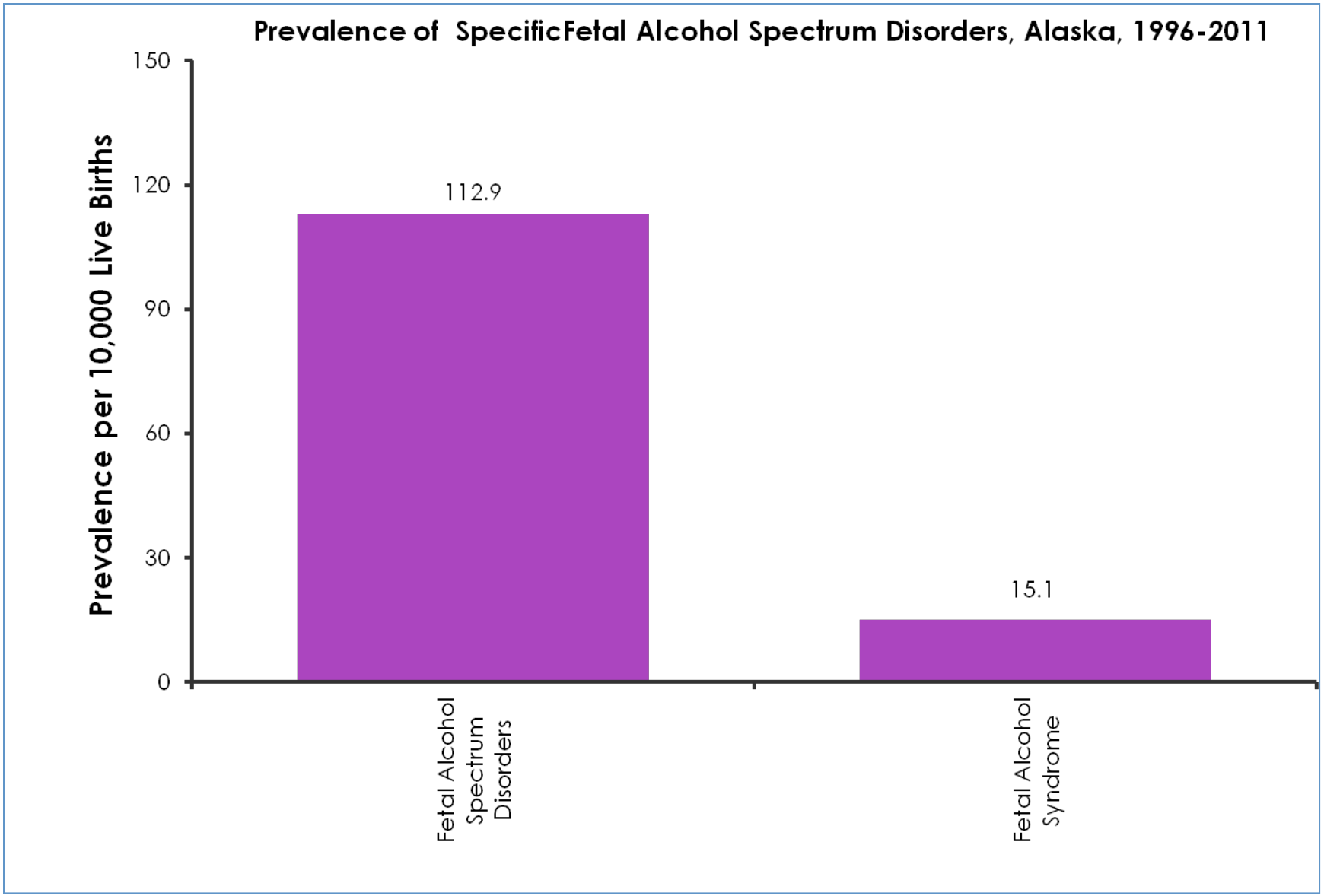
How Common is FAS/D in Alaska?

FAS – *About 1.5 in 1,000 Alaskan children are born with FAS every year (15.1 in 10,000)*[1]

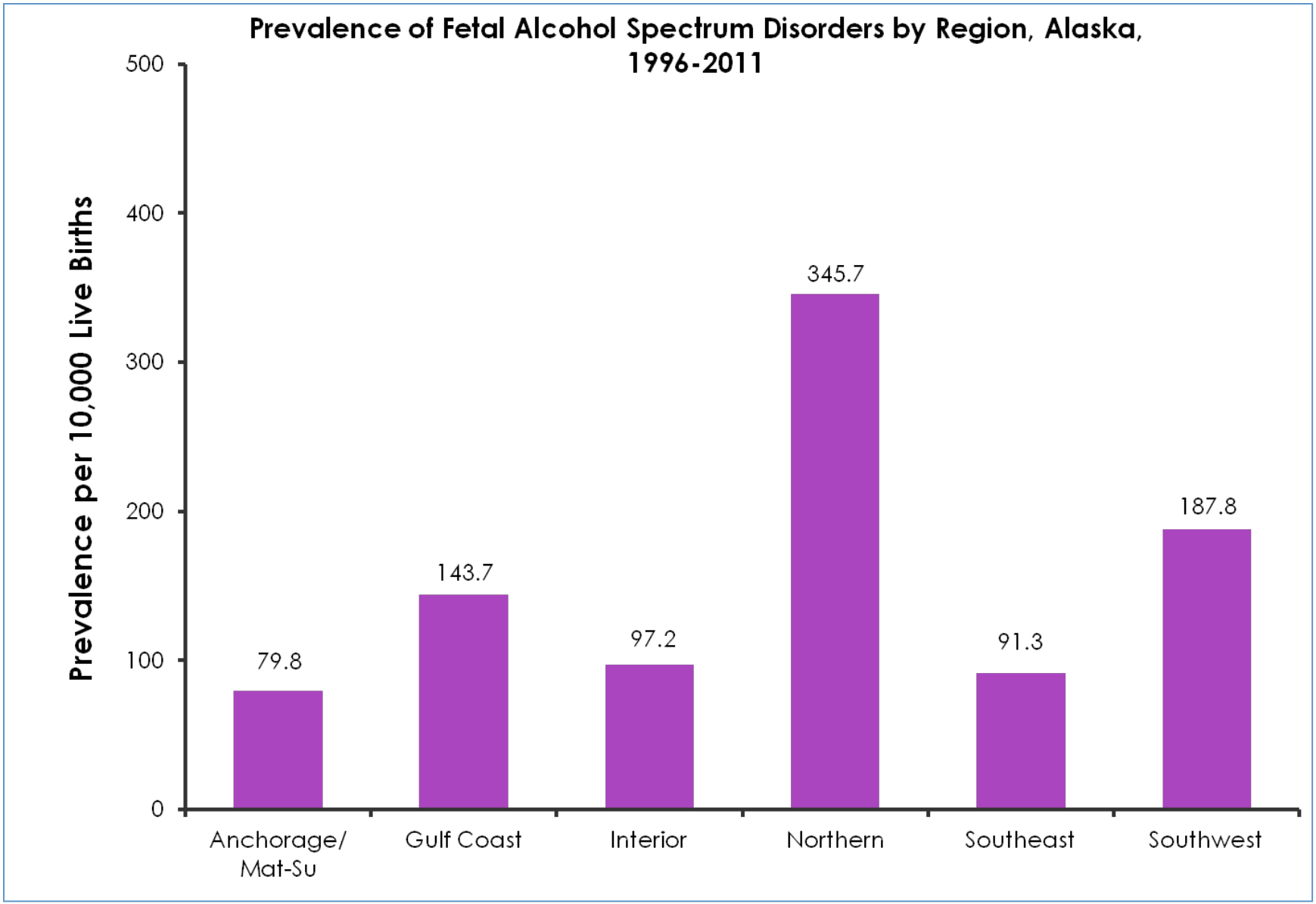
FASD *(including FAS, ARBD and ARND) – About 13 in 1,000 Alaskan children are born with one of the diagnoses on the FASD spectrum every year (112.9 in 10,000)*

Source: *Alaska Birth Defects Registry (ABDR), Division of Public Health, Alaska Department of Health & Social Services.*

[1] ***Method:*** *During 2009, medical record abstractions were completed for all potential FAS cases reported to the ABDR for children who were at least 6 years of age (birth years 1996-2002). Data from these abstractions was linked to birth certificates and the linked file was used to determine FASD prevalence estimates. Confirmed FAS cases met the following criteria: matched an Alaska birth certificate; were reported to ABDR before age 6 years; and had at least on complete medical chart abstraction. Because children may be reported up to their 6th birthday, prevalence beyond 2006 may be underestimated.*



Source: *Alaska Birth Defects Registry, Division of Public Health, Alaska Department of Health & Social Services*



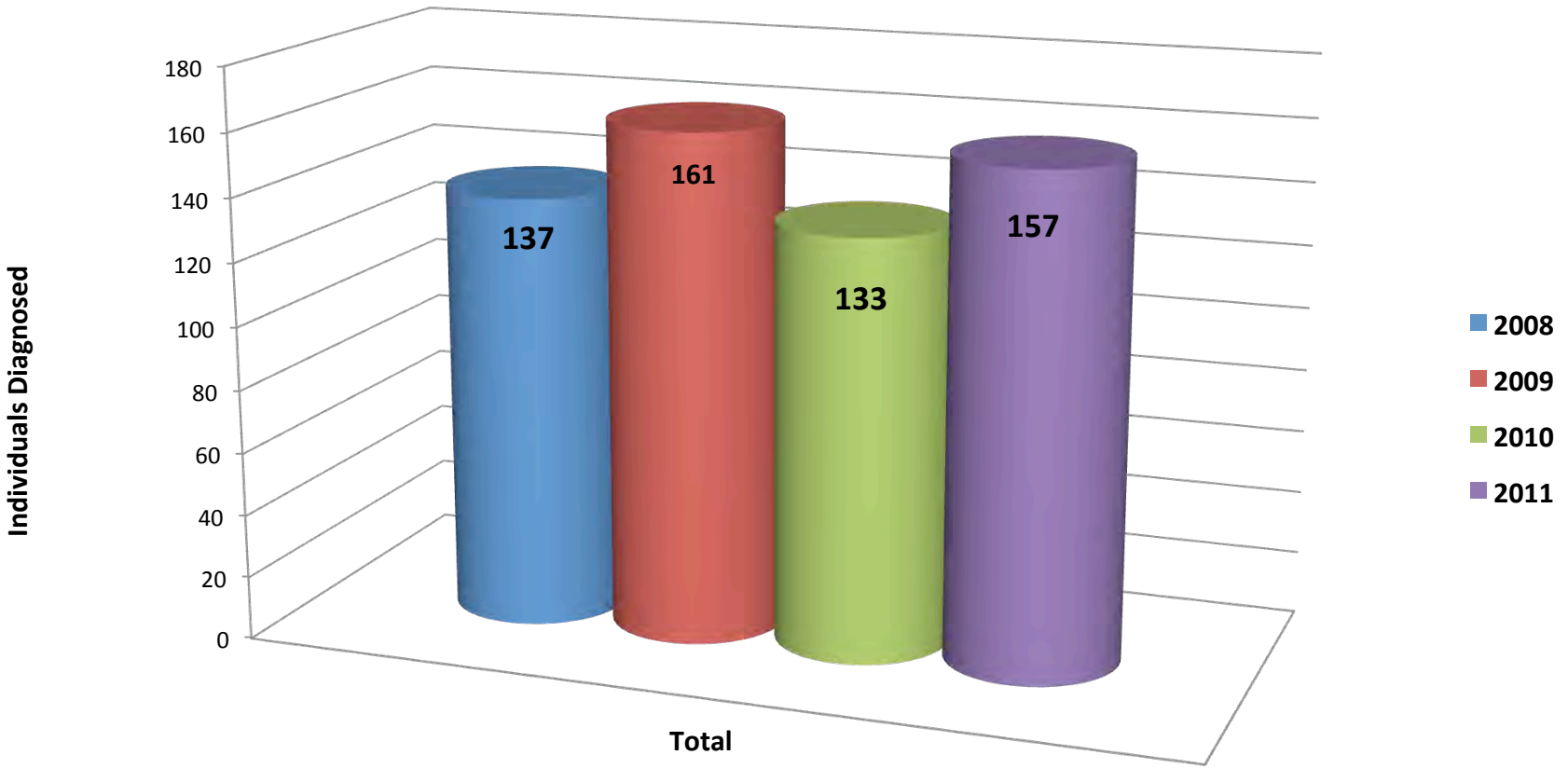
Source: *Alaska Birth Defects Registry, Division of Public Health, Alaska Department of Health & Social Services*

FASD Diagnosis in Alaska

- *There are currently six active diagnostic teams in Alaska:*
  - *Assets FASD Diagnostic Team (Anchorage)*
  - *Southcentral Foundation FAS Diagnostic Team (Anchorage)*
  - *Yukon-Kuskokwim FASD Diagnostic Team (Bethel)*
  - *Fairbanks Fetal Alcohol Community Evaluation Services (Fairbanks)*
  - *Kenai Peninsula FASD Multidisciplinary Team (Soldotna)*
  - *Sitka Neurodevelopmental Clinic (Sitka)*

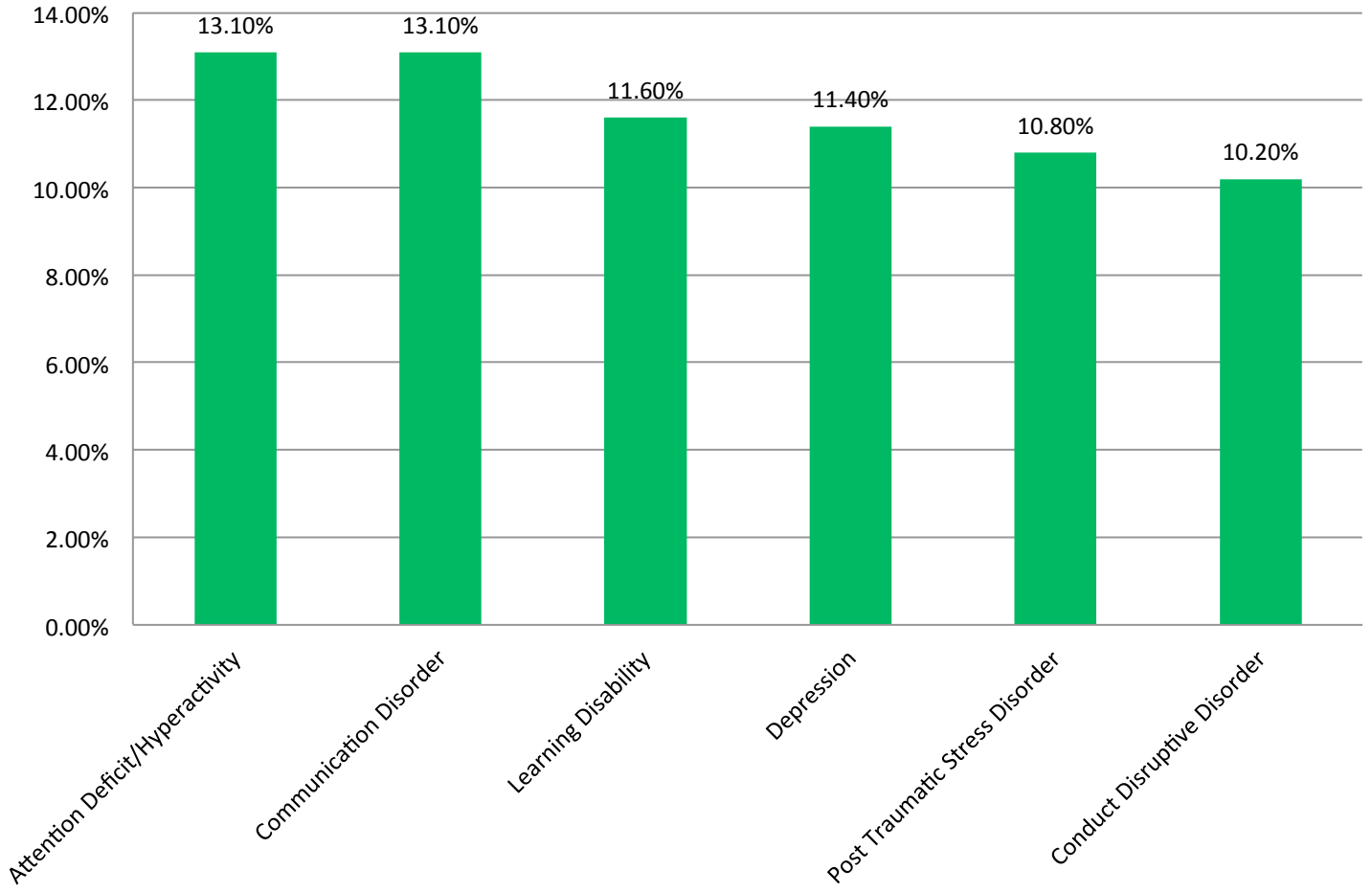
- *Each team uses the 4-Digit Diagnostic Code, developed at the University of Washington and considered the "gold standard" for diagnosing the full spectrum of outcomes from patients with prenatal alcohol exposure.*

Number of Individuals Diagnosed with FASD in Alaska 2008-2011



Source: *Alaska Department of Health & Social Services, Division of Behavioral Health*

Top Psychiatric Diagnosis for Alaskans Diagnosed By FASD Teams



Source: *Behavioral Health Research Services, FAS Evaluation, Alaska Multidisciplinary FASD Teams Chart Review Data, Page 42, November 30, 2005, N=352*

How Common is FASD in the United States?

FAS - *Studies from different regions of the U.S. indicate that 0.2 to 2 in 1,000 live births have FAS.*[1]

ARBD and **ARND** - *Researchers believe there are at least three times as many cases of FASD as FAS in the United States, about 10 in every 1,000 live births.*[2]

About 40,000 children are born with an FASD every year in the United States

[1] ***Source:*** *Centers for Disease Control and Prevention (CDC). http://www.cdc.gov/NCBDDD/fasd/data.html.*

[2] ***Source:*** *Centers for Disease Control and Prevention (CDC) (2011); and Sampson PD, Streissguth AP, Bookstein FL, Little RE, Clarren SK, Dehaene P, Hanson JW, Graham JM Jr. Department of Statistics, University of Washington, Seattle. (1997).*

What are some common difficulties experienced by people with FASD?

- *Hyperactivity, attention deficits, memory deficits*
- *Impulsivity, not thinking before acting or speaking*
- *Socially immature, hangs out with younger people*
- *Inappropriate behavior, overly friendly to strangers*
- *Difficulty with spatial awareness, bumping into things*
- *Difficulty completing tasks, organizing*
- *Difficulty understanding and remembering rules*
- *Difficulty with abstract concepts, managing time and money*

continued …

… continued

- *Lower than average IQ in about 10% of those with FASD*
- *Short-term memory deficits – can't remember instructions*
- *Difficulty accessing information on demand*
- *Poor sensory integration*
- *Difficulty with math (dyscalculia)*
- *Difficulty with reading*
- *Developmental delays in language, motor and social skills*
- *Development of secondary disabilities (not caused by FASD, but resulting from it) – such as depression, substance abuse, sexual promiscuity, difficulty holding a job, homelessness.*

What are some common strengths in people with an FASD?

- *Tenacity, determination, persistence, strength of character*
- *Friendly, outgoing, affectionate*
- *Creative, artistic, musical, mechanical*
- *Expressive language skills*
- *Athletic, agility, fearlessness*
- *Learns easily by watching and doing (visual/kinesthetic)*
- *Helpful, willing, generous*
- *Sensitivity, awareness of others' emotions and feelings.*

IQ in people with an FASD

- *The average IQ of a person with an FASD is 75–85*
- *The full range of IQs among persons with an FASD is between 20-140+* [1]
- *Almost all individuals with an FASD have an Adaptive Quotient (AQ) * of greater than 70* [1]
- *In adults with FASD, 80% are unable to live independently, regardless of IQ* [2]

* *Adaptive Quotient (AQ) measures ones ability to function without supports in the areas of communication, socialization, daily living, time management, employment, etc.).* [1]

[1] ***Source:*** *Russel, IQ—It Just Doesn't Matter: The Role of Adaptive Functioning in Individuals with FAS/FAE/ARN. FASD Conference: Doing What Works, Vancouver 2003*

[2] ***Source:*** Streissguth, Bar et al. *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE); Centers for Disease Control and Prevention Grant no. RO4/CCR008515 (1996)*

Signs of FASD in infancy and early childhood

- *Fitful sleep patterns*
- *Poor suck reflex*
- *Poor muscle tone*
- *Delays in walking and toilet training*
- *Small in height and weight*
- *Temper tantrums*
- *Overly sensitive or under responsive to stimulation*
- *Lack of stranger anxiety*
- *Possible attachment difficulties*

Source: *U. S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA), Fetal Alcohol Spectrum Disorders Center for Excellence.*

… in middle childhood

- *Possible hyperactivity*
- *Poor memory*
- *Lack of impulse control*
- *Poor social skills*
- *Failure to understand consequences*
- *Very concrete thinking*
- *Onset of academic problems*

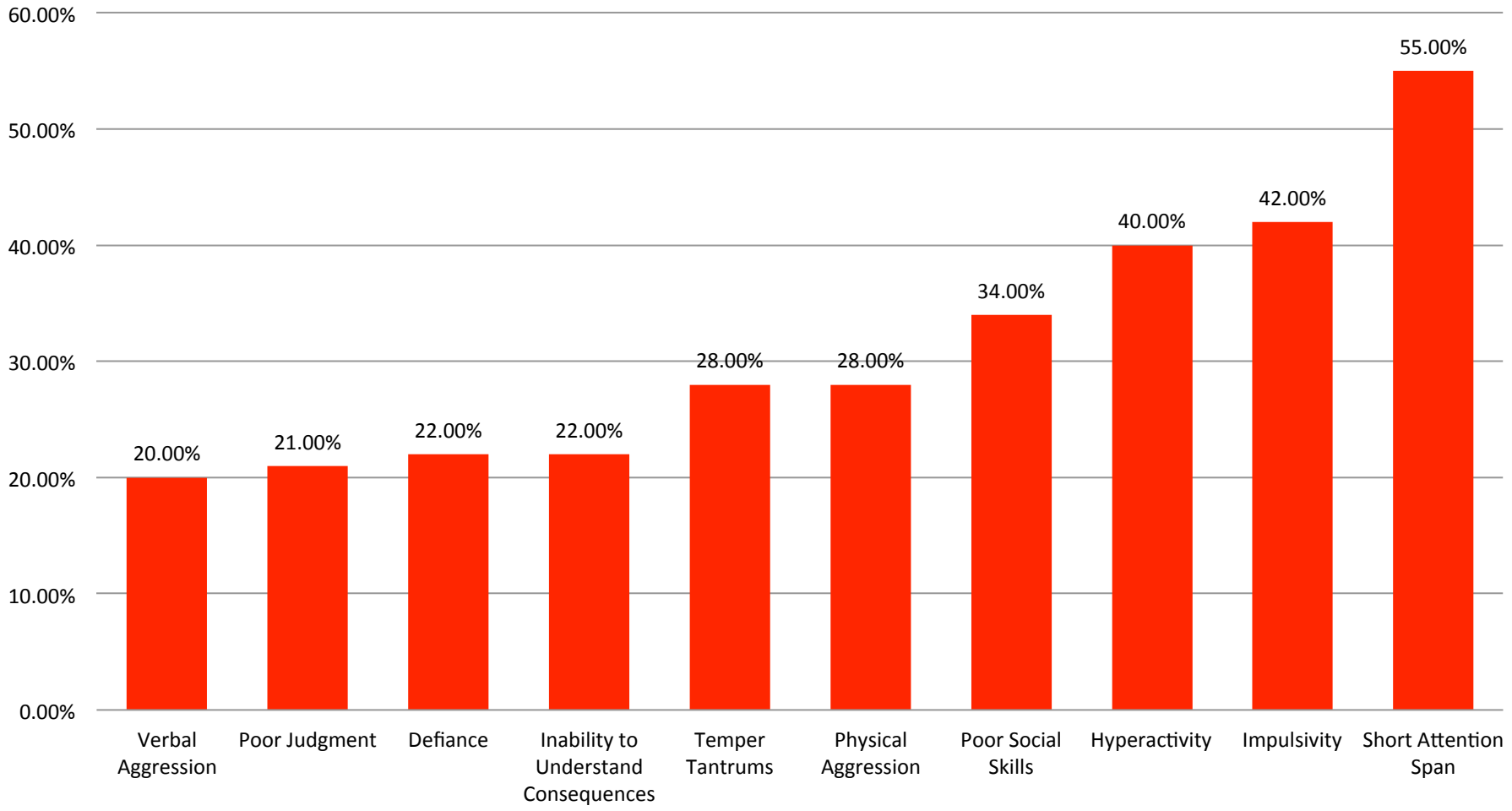
Source: *U. S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA), Fetal Alcohol Spectrum Disorders Center for Excellence.*

… in adolescence

- *In FAS, less obvious facial features*
- *Poor judgment and impulsivity*
- *Signs of depression*
- *Alcohol and drug use*
- *High risk of pregnancy, sexually transmitted diseases, HIV, and other related problems*

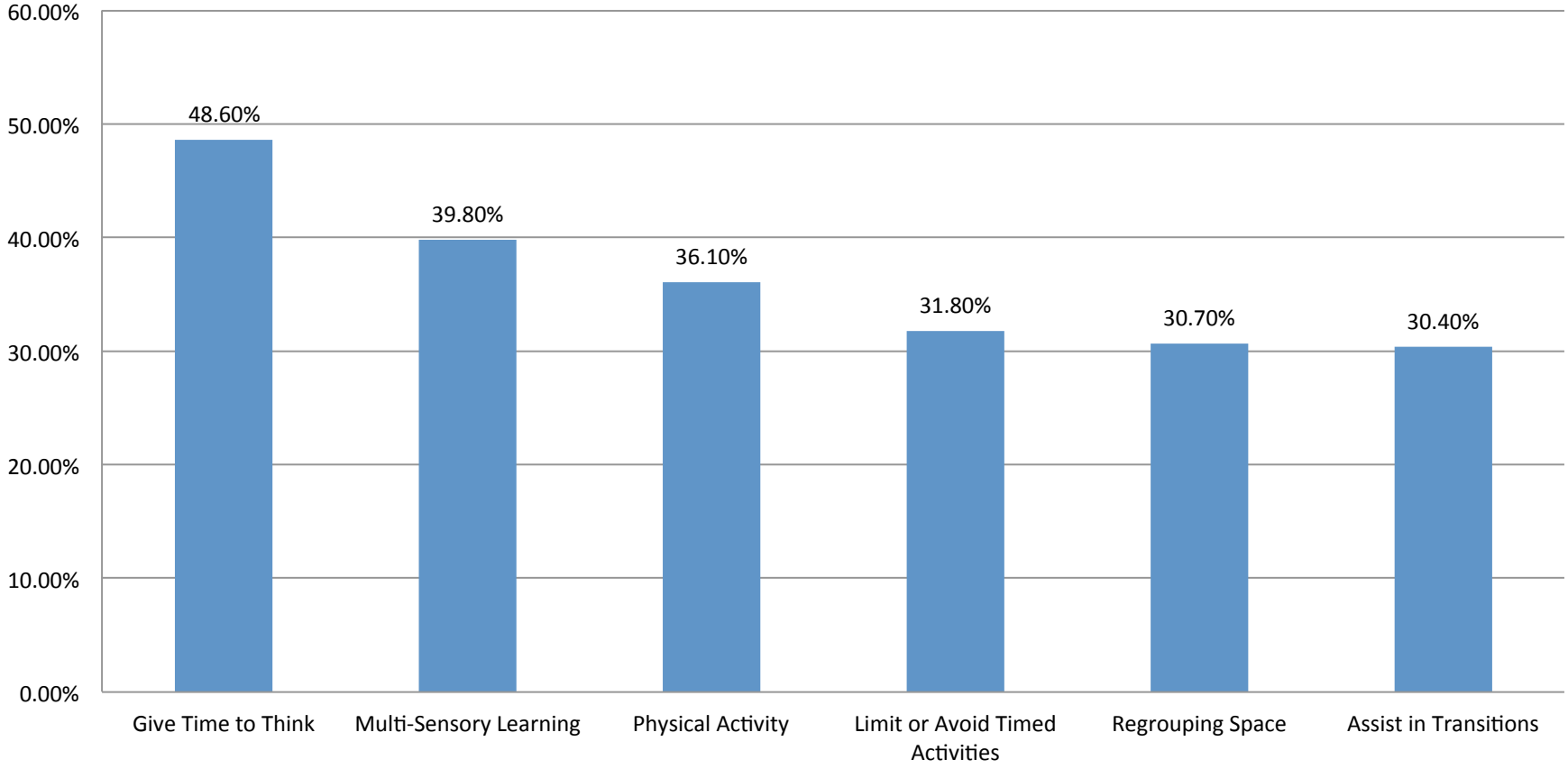
Source: *U. S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA), Fetal Alcohol Spectrum Disorders Center for Excellence.*

Top Disruptive Classroom Behaviors of Alaskan Children Diagnosed by FASD Teams



Source: *Behavioral Health Research Services, FAS Evaluation, Alaska Multidisciplinary FASD Teams Chart Review Data, Page 23, November 30, 2005, N=352*

Top Recommendations To Schools for Techniques of Positive Interaction for Alaskans Diagnosed by FASD Teams



Source: *Behavioral Health Research Services, FAS Evaluation, Alaska Multidisciplinary FASD Teams Chart Review Data, Page 39, November 30, 2005, N=352*

Strategies for Success

- *Understand and teach that FASD is a brain-based disability with behavioral symptoms*
- *Educate the person with FASD about their disability and offer tools for managing it*
- *Understand that traditional behavioral treatment techniques a re frequently ineffective for people with FASD*
- *Offer supports, not consequences*
- *Use strength-based approaches, do not blame or shame*
- *Be consistent, concrete and incorporate structure*
- *Understand and teach the importance of nutrition and exercise*

Structure

….a few examples

- *Needs an "external brain"*
- *Consistency with time, schedules, language*
- *Smooth transitions-between activities, home and school*
- *Allows time for longer thought processing*
- *Offer lists and written instructions, choices*
- *Reminding without blaming*

“If a child cannot learn in the way we teach, we must teach in a way the child can learn.”

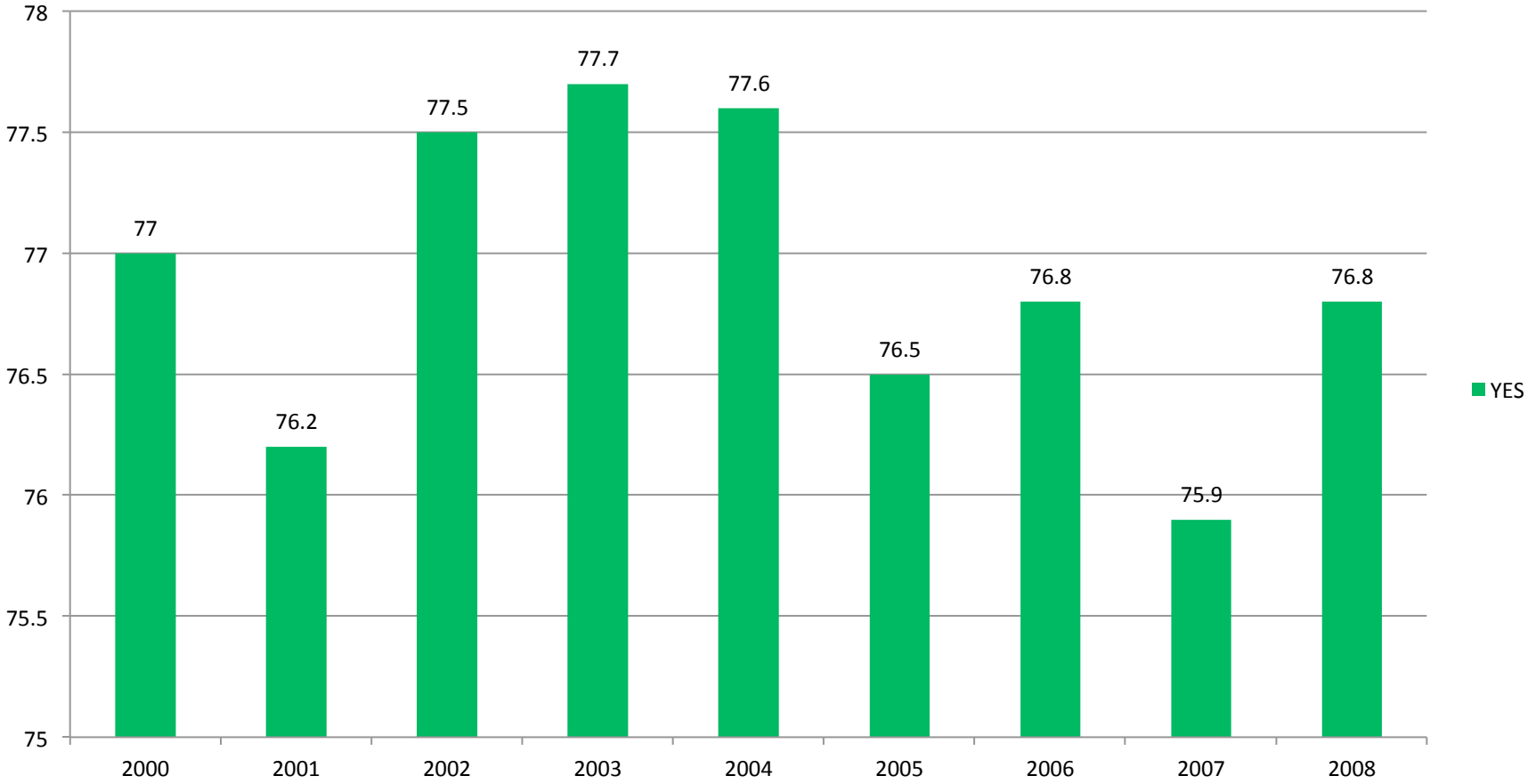
– Dr. O. Ivar Lovaas

Women & Pregnancy

- *In the United States, about 13% of fetuses (520,000 annually) are exposed to alcohol during pregnancy, most at very low levels and only early in pregnancy.* [1]
- *One of every four Alaskans dependent on or abusing alcohol is a woman, and one of every 25 women whose babies are born alive said she drank while pregnant, according to the Center for Behavioral Health Research and Services (UAA).*

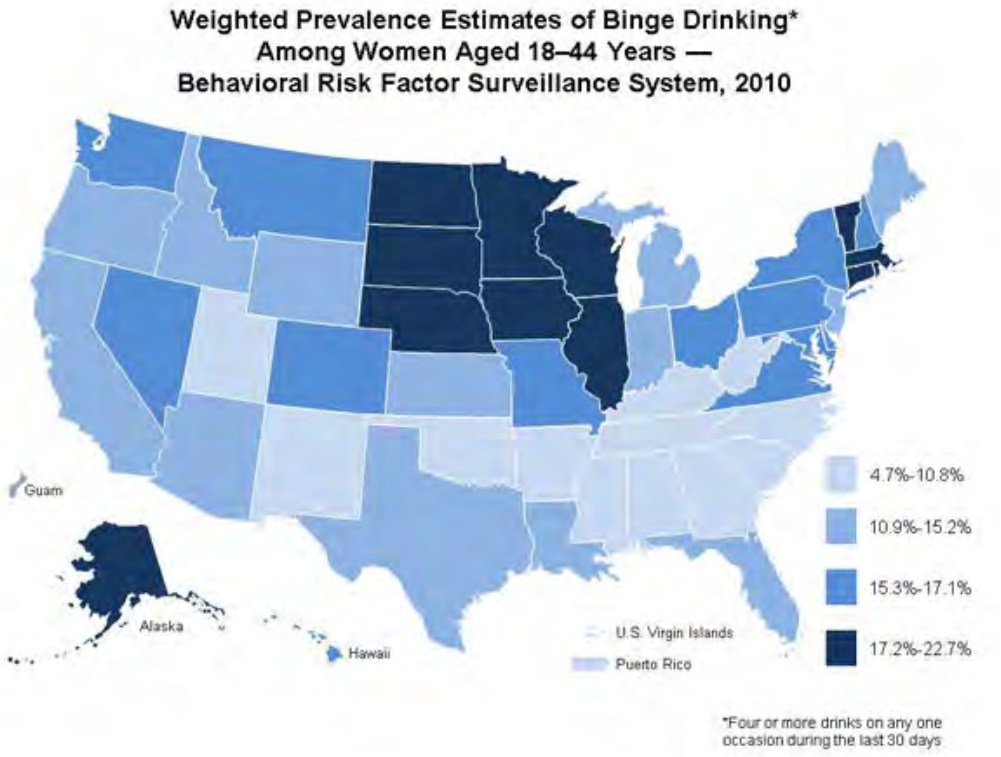
[1] ***Source:*** *Centers for Disease Control. Alcohol use among women of childbearing age--United States, 1991-1999. MMWR Morb Mortal Wkly Rep 2002; 51(13):273-276.*

Percentage of Alaskan Mothers Who Reported that Their Health Care Provider Discussed Alcohol's Affect on Their Developing Baby During Prenatal Care Visits



Source: CPONDER – Center for Disease Control's, Pregnancy Risk Assessment Monitoring System (PRAMS): On-line Data for Epidemiologic Research, http://apps.nccd.cdc.gov/cPONDER/default.aspx?page=category&state=1&year=0&category=2

Binge Drinking in Women of Childbearing Age



Source: *Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Division of Birth Defects and Developmental Disabilities* http://www.cdc.gov/ncbddd/fasd/data.html

Economic Costs in Alaska Related to FAS

Original and Adjusted Estimates of the Total U.S. Lifetime Cost for Each Child Born With Fetal Alcohol Syndrome (FAS)

Source of estimate	Original estimate of total U.S. lifetime cost of child born with FAS	Adjusted 2002 estimate of total U.S. lifetime cost based on inflation	Discounted estimate of total 2002 U.S. lifetime costs after adjustment for inflation
Harwood and Napolitano [Harwood et al., 1985]	$596,000	$2,010,000	$931,742
Alaska State Legislature [Weeks, 1989]	$1,373,836	$2,909,785	$1,466,875

Source: *Cost of Fetal Alcohol Spectrum Disorders, CHUCK LUPTON,* LARRY BURD, AND RICK HARWOOD,* *ftp://senfiles.healthystartfv.org/Sort%20Literature%20Review.Data/30015_ftp-2928697097/30015_ftp.pdf*

Using 2002 Figures (not inflated), the 150* children born with FAS between 2002 & 2011 (15 per year) will cost $220,031,250 in their lifetimes.

** For the purposes of this analysis, 10,000 births a year were used. The average for the 10-year span per the Alaska Bureau of Vital Statistics was slightly higher than 10,000 and the rate of FAS births was rounded from 15.1 to 15.0 per 10,000 births. Analysis by AMHB/ABADA Staff*