

FASD: Using Data to Tell Stories

Part I: The Data

- Sandy Collins, MPH, RD
Alaska Birth Defects Registry Coordinator
- Janine Schoellhorn, MS, MPH
Lead Epidemiologist and Data Analyst
- Alaska Division of Public Health
Section of Women's, Children's and Family Health
MCH Epidemiology Unit
- <http://www.epi.hss.state.ak.us/mchepi/programs.stm>



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Acronyms

- **ABDR** — Alaska Birth Defects Registry
- **CDC** — Centers for Disease Control and Prevention
- **CNS** — Central Nervous System
- **FAS** — Fetal Alcohol Syndrome
 - Subset of FASD
 - No ICD9 code for FAS
- **FASD** — Fetal Alcohol Spectrum Disorders
 - ABDR uses ICD9 760.71
- **FASSNet** — Fetal Alcohol Syndrome Surveillance Network
 - CDC-developed methodology used to identify FAS cases for surveillance purposes



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Background – FASD surveillance in Alaska

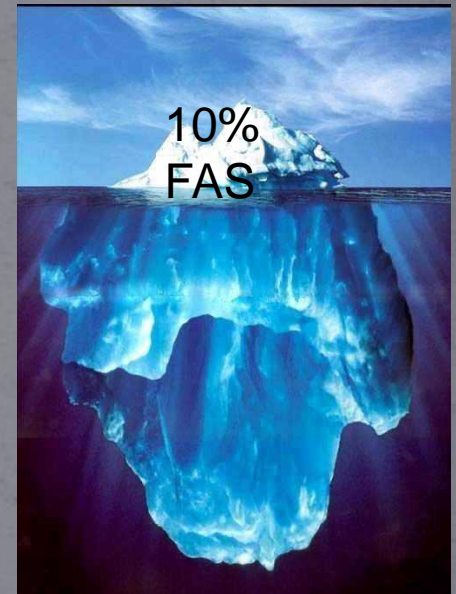
- Conducted by the Alaska Birth Defects Registry
- Based on reports of 760.71 (infant affected by prenatal alcohol exposure) to the Registry
 - Used as basis for determining children at risk of FAS and for case verification activities to quantify children with FAS
- Reporting is required of health care providers who screen, diagnose or treat children up to the age of six



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FAS is the tip of the FASD iceberg

- Many individuals are born affected by prenatal alcohol exposure but don't meet the full criteria for FAS (face, CNS, growth)
 - These individuals may still exhibit:
 - learning disabilities
 - hyperactivity
 - mental health issues
 - problems with the ability to pay attention, memory, and problem solving
 - other birth defects



What does ABDR data reveal about FASD in Alaska?

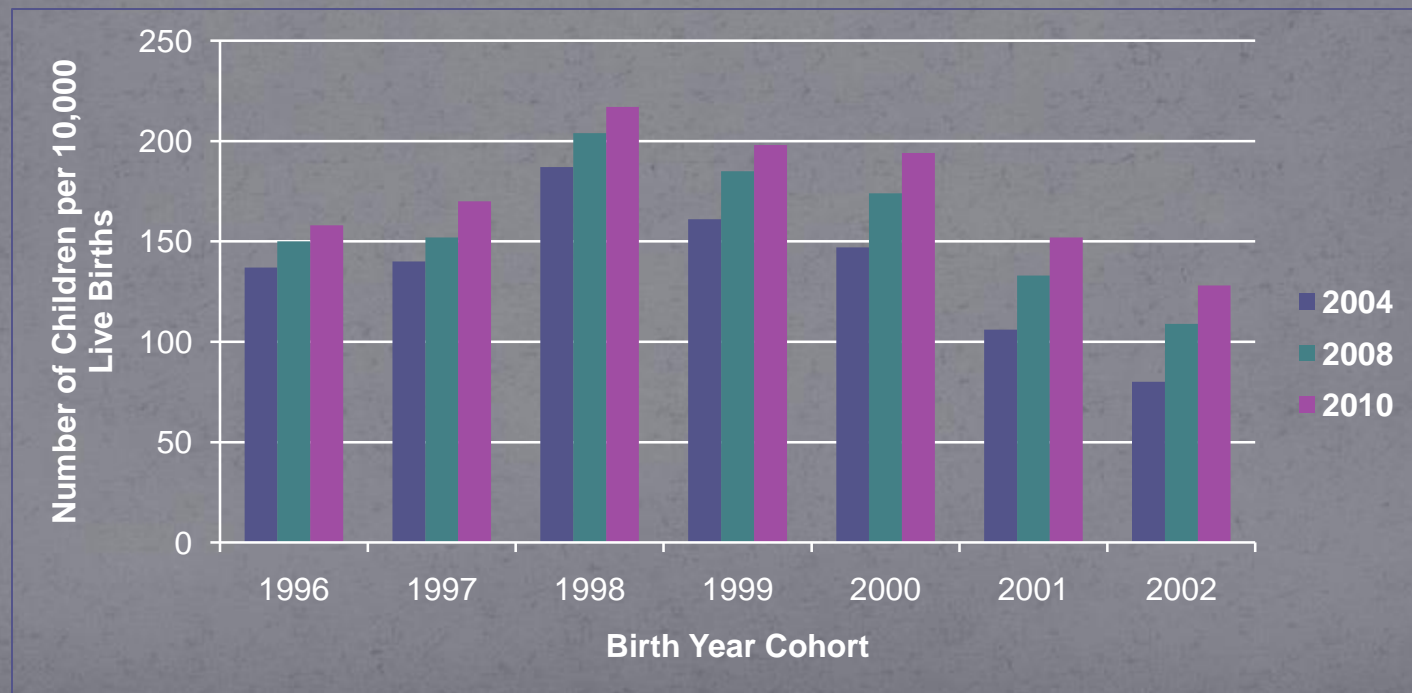
- 1. There is a declining trend in reports of FASD (ICD-9 760.71) to the ABDR with more recent birth years, but the number of reports for any given birth year increases as the cohort ages
- 2. Children reported with 760.71 are more likely to “make case” for FAS with increasing age
- 3. FASD data must be standardized to get a true picture of trends
- 4. There is a declining trend in FAS prevalence in Alaska
- 5. Although we observe declining trends in FAS and in reports of 760.71 to the ABDR, FAS prevalence in Alaska is high (when compared with other states) as is the cost associated with having FAS



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1. There is a declining trend in reports of FASD to the ABDR, but the number of reports for any given birth year increases as the cohort ages

Number of children with reports of 760.71 (FASD) to the Alaska Birth Defects Registry, birth years 1996-2002 as of 12/2004, 7/2008, and 7/2010



2. Children are more likely to “make case” for FAS with increasing age

- The most recent birth cohort year for which we have data that we have analyzed is 2002
 - This data is not “old” – it is current in that
 - We have mandatory reporting for children up to age six, and
 - Children are more likely to make case as they reach school age
 - We have recent medical record abstraction data on those children
 - Medical record abstraction takes time
 - For the 2002 birth year
 - Children turned age six in 2008
 - Medical record abstractions were completed and data was analyzed in 2009
 - Epi Bulletin published in February 2010



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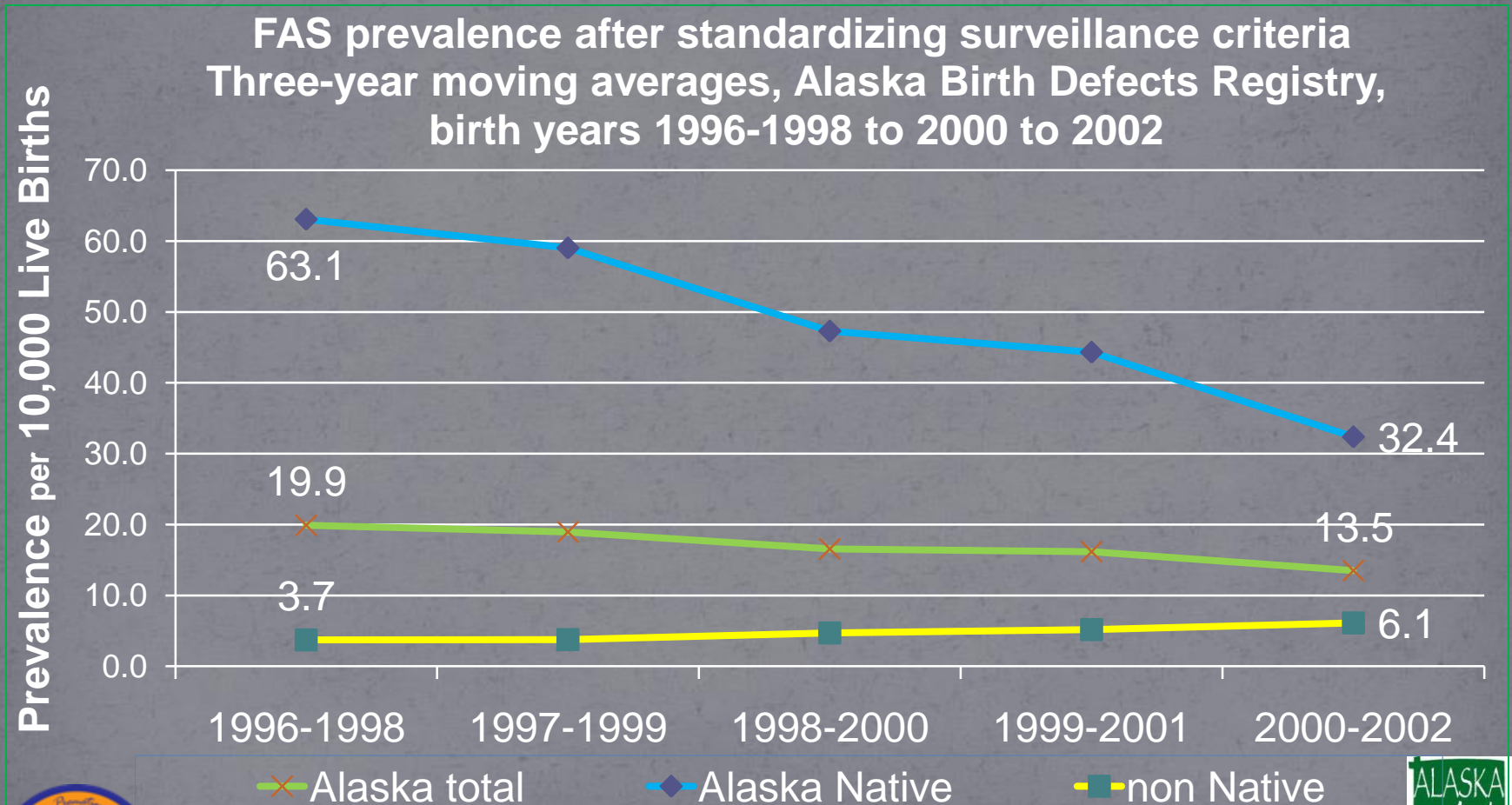
3. FASD data must be standardized to get a true picture of trends

- Because there is no case definition for FASD, in order to systematically analyze trends we must look at the subset of children with FAS, which has a surveillance case definition
- We must standardize the data in order to “compare apples to apples”
- Standardization of the FASD data requires that children:
 - Are matched to an Alaska birth certificate
 - Are reported to the ABDR with a qualifying condition (ICD-9 760.71)
 - Are reported to the ABDR by age six
 - Have had at least one recent medical record abstraction



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4. There is a declining trend in FAS prevalence in Alaska



5. Although we observe declining trends in FAS and in reports of 760.71 to the ABDR, FAS prevalence in Alaska is high (when compared with other states) as is the cost associated with having FAS

- The lifetime costs associated with having FAS are estimated at \$2 million*
 - These costs do not include those associated with the caregiver of an individual with FAS, such as lost productivity
- Individuals who do not have all the characteristics of FAS may still incur costs that may be associated with:
 - learning disabilities
 - hyperactivity
 - mental health issues
 - problems with the ability to pay attention, memory, and problem solving
 - other birth defects



*Source: <http://www.fasdcenter.samhsa.gov/publications/cost.cfm>



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At an estimated lifetime cost of \$2 million...

- The estimated total cost to individuals included in the trend analysis who met the case surveillance definition of FAS born in Alaska between 1996 and 2002 is

\$240 million for 120 individuals

- This does not include costs for those who were reported but did not meet all of the surveillance case criteria for FAS or the standards for analysis (totalling about 1250 individuals for birth years 1996-2002), for example:
 - individuals with other FASDs
 - individuals with FAS who live in Alaska but who could not be matched to an Alaska birth certificate
 - individuals with FAS who were reported to the ABDR after age six



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Data challenges

- Categorizing children with FASD
- Inclusion/exclusion of children that do not meet case criteria
- Making data useful to the FAS community



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In the end, every number represents a child

- And every child has a story
 - Those stories are full of challenges...
 - Those stories are full of successes...



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Thank you!

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USING DATA TO TELL STORIES

PART II: THE STORIES

Marilyn Pierce-Bulger, FNP, CNM, MN
FASD Diagnostic Team Coordinator, Assets, Inc. and Consultant

Declining FAS Trends Reflect What?

- IHS prenatal alcohol screening began 1980's
- Vestiges of those programs remained with tribal compacting in 1990's
- AI/AN community has acknowledged the concerns about high alcohol use rates
- \$29 million efforts from SAMSHA grant '00-'05
 - Diagnostic teams
 - Education efforts
 - Public campaign
 - Service delivery shifts

Making Data Useful to the FASD Community

- Regional/local reporting?
 - Nutaqsiivik example
- Tracking sources – acknowledge those who are doing it well, prod those who are not?
- Do we need to focus on the non-Native community now with our messaging?
- Do we need to give providers a script for how to discuss unintentional exposures with women?
 - Pregnancy wheel example

Types of Data

- Improvement
 - Identifying problems or improvement opportunities
 - Process improvement team gets baseline info
 - Measuring after improvement trials
- Accountability
 - Outcome/results focused
 - Do not show how outcome was achieved or how process can be changed
- Research
 - Can be too slow, expensive and elaborate for benefiting processes

Improvement Project Perspective

- What are we trying to accomplish?
 - Identify individuals with prenatal alcohol exposure at a younger age
 - Convey ETOH risk information in records/to pediatric providers
 - Preschool expulsions
 - Avoid secondary disabilities
 - M's story
 - Create effective systems of care/support for individuals/families
 - R's story
 - Juneau Diagnostic Team ID card for those w/FASD

Improvement Project Perspective

- What changes can we make that will lead to improvement?
 - Inform & motivate the public about FASD....alcohol use in pregnancy is a significant problem for the fetus
 - Inform & motivate the providers about FASD prevention and identification
 - Track what happens to individuals/families after diagnosis

Improvement Project Perspective

- How will we know there IS an improvement?
 - Capture stories!
 - ABDR data is one way
 - Public awareness/KAB surveys/PRAMS data
 - Systems have changed to become more responsive to individuals with FASD
 - DOC example from Canada; PO here....
 - Anchorage School District work with Deb Evensen

Remember.....

- Every number reflects a life....the quality of that life may differ due to the impact of prenatal alcohol exposure but....
- We are meant to learn from this experience for future generations and....
- Those affected have amazing stories to share....we must thoughtfully observe & listen.