



**Quality of Life for Alaskan
Individuals with Fetal
Alcohol Spectrum Disorder
and Implications for their
Families**

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Learning Objectives

At the end of the presentation:

- The participant will consider at least four ways that FASD has affected quality of life for some affected individuals in Alaska.
- The participant will consider at least four ways the family has been affected by having an individual with FAS/FASD in the home.
- The participant will be able to discuss some school supports that were helpful for individuals with FASD.
- The participant will be able to describe areas where additional supports are needed by individuals with FASD or family members.

Why is research on FASD important in Alaska?

- Alaska ranks first in the United States for babies born with prenatal exposure to alcohol
- 2016 McDowell Report for the State of Alaska estimates the rate of FASD in Alaska at 11.3 per 1000 births
- 2006 Behavioral Health Research and Services study estimated that 27% of the state inmate population has FASD
- There is little research on FASD in Alaska
- **None has been done on quality of life questions**

Methodology

- Followed the Institutional Review Board (IRB) protocol
 - All individuals signed Informed Consent forms
- Twenty-two semi-structured in-depth interviews
 - 8 interviews – Individuals with FASD eighteen years of age or older
 - 14 interviews – adoptive or long-term foster parents
 - 18 cases total – some parents/individuals were from the same families
- All interviews audio taped and transcribed by myself
- Interviews were read and coded
 - Themes and patterns
 - Comparing to findings from the Literature Review

Cases

- Ages: 6 years to 35 years of age
- Four cases under 18: interviewed only parents
- Conducted mainly in interior Alaska
 - Majority of cases from rural Alaska, brought into Fairbanks for foster care or adoption
 - Two cases were born outside of Alaska but adopted in Alaska
- Majority were Alaska Native
 - High incidence of FASD in Alaska across most ethnic groups
 - Disproportionate number of Alaska Natives in foster care system
- Diagnoses: FAS: 6; FAE: 1; FASD: 8; ND-AE:2; SE-AE: 1

Research Questions

- 1) How has FASD impacted quality of life for affected individuals?
- 2) How has raising individuals with FASD affected quality of life for families?
- 3) What supports were most helpful to the affected individual or the family?
- 4) What supports not currently provided would be helpful to individuals with FASD and families?

Findings similar to those found in the literature:

- All eighteen individuals with FASD experienced Adverse Childhood Experiences (ACES)
 - All removed from their biological mothers due to abuse/neglect
 - All experienced multiple placements
 - Seldom placed with their siblings
 - One of the 18 placed with family members
 - Twelve placed outside of their culture
 - Ten of the 14 individuals over 18 years of age went to residential treatment centers - 3 in out-of-state placements

Difficulties Can Arise When Siblings are Placed Together

One young man related to me:

“There was me and my younger brother and sister. It was one of those things where one foster kid isn’t bad but when you have three young ones it makes it a little bit harder, especially with higher needs like we had ... behavior issues or stuff like that. It took a toll on many different foster families. It was one of those things where they didn’t want to split us up but they couldn’t care for us as a group. We went through a large number, at least seven different foster homes before we were adopted.”

All experienced difficulty in school and needed additional educational services:

- Struggled more as they progressed through school
- Eleven out of 14 graduated (79 percent)
- Experienced difficulty with comprehension and memory
- Needed a highly structured classroom environment and fixed routine
- Difficulty with homework
- Difficulty with social skills/friendships
- Isolation/victimization

Adult individuals with FASD shared:

“It’s made it so I have problems catching social cues and made high school really hard because I could never catch the social cues and I was always offending someone. And no one really wanted to hang out with me. That’s why I spent time at the library every lunch break. But I have learned how to cope with that and I’ve been able to catch it most of the time.”

“It was pretty hard. I got bullied a lot most of the time. And after the years I got used to it but it is still stressful.”

How has FASD impacted quality of life for the fourteen affected adults?

- Ages of cases between 18-35
- Thirteen met criteria for a mental health DSM diagnosis
- Ten went to residential treatment as adolescents
- Six hospitalized in a psychiatric facility
- Twelve (86%) experienced confinement in detention, jail, prison, psychiatric, or alcohol/inpatient setting compared to Streissguth et al.'s 2004 finding that 50% of the individuals interviewed experienced confinement

Serious Difficulties with Transitions to Adulthood

- Thirteen of the fourteen adults experienced significant challenges
 - The one without difficulties just graduated high school and was still at home
- Ability to live independently
 - Eight individuals live “independently”
 - Two in low income housing
 - One in their own residence on the parent’s property
 - Other six
 - One lives in assisted living
 - Three continue to live in their family home or foster home
 - One works a job that provides housing, lives at home when in town
 - One is homeless

Many Need Assistance with Money Management and other Tasks

- Money Management
 - Six receive assistance in managing their money
- Medication Management
- Employment
 - Six work full-time
 - Five work part-time
 - Four need special accommodations at work:
 - Job Coach, Prompts, Ability to take time to decompress when stressed
 - Reliable Transportation

Other Adult Challenges

- Finding affordable housing -- a past foster parent of a 30 year old female stated:

“So she lives in “dive” places or she was living in places that were not good. Her son got MERSA in July 2016 which was a result of the apartment... just really horrid conditions.”

- Other struggles:
 - Relationships
 - Parenting
 - Accessing services
 - Taxes, other paperwork
 - Making and keeping appointments

Not Being Ready for Adult Responsibilities

- Chronological age doesn't equal developmental age or maturity
- Significant in Alaska
 - Alaska Permanent Fund Dividend (PFD): Constitutionally established permanent fund established in 1976 that manages the state's assets from oil revenues
 - Every state resident receives a check each year.
 - Dividends of children in foster care are held in trust.
 - Alaska Native Regional Corporation Dividends: Dividends from corporations established in 1971 to settle Native land claims

“He had just gotten his Native money and unbeknownst to us he had taken it all out of the bank, \$5000, and he had it in his apartment...He showed her [a friend], “look what I have.” He was so proud of himself. Well, about 6 hours later it was gone.”

Effects on the Family

- Need for additional structure, routine and consistency
- Ongoing household and personal stress
 - Tired due to lack of sleep/high demands
 - Growing awareness that your child may never become independent
 - Loss of friendships
 - Marital relationship problems
 - Siblings not having their needs met
 - Lack of personal time
 - **Compassion fatigue**

Accommodations help

“He was in the school district building and there were only five kids in the class and one teacher. She just adapted everything for him. She would give him a text book here and then at the other end of the long cubby or desk was his worksheet. And she put him on a rolling stool and he would roll back and forth, back and forth. He would roll to the book and then back down to the worksheet.”

... but they don't resolve the underlying problem.

Some figure out what works

“He goes to school and he doesn’t go straight to the classroom because it is too loud and there’s too much going on so he goes straight to the resource room. They have him doing physical therapy so he throws balls into a hoop, weighted balls, he would go into this weighted roller thing and put a puzzle together and then put him in a swing and turn the lights down. He’d only be there for fifteen minutes or so. And by the time he went to the classroom, it was calm.”

Thank you!

Questions?

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