

# The Person Behind the Face of Fetal Alcohol Spectrum Disorder: Student Experiences and Family and Professionals' Perspectives on FASD

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## Abstract

This article describes the individual experiences of 5 students with Fetal Alcohol Spectrum Disorders (FASD) living in rural and urban Alaska. The article is based on the results of a 3 year qualitative study using interviews with and observations of the students, members of their family, and educational and medical professionals with whom they are involved. Findings highlight several major themes that include: (a) the person behind the face of FASD; (b) experiences of students with FASD including situations of competence and vulnerability; (c) anticipated trajectories that lead the students towards experiences of separateness and isolation; and (d) the social and cultural stigma of FASD. The article concludes with recommendations that service providers, educators, and policy makers can use to improve the education and community life for students with fetal alcohol spectrum disorders.

Thirty years ago a diagnosis of Fetal Alcohol Syndrome (FAS) or other alcohol related birth defects was rare. In 2004, however, such a diagnosis is not unusual in towns, villages, and cities in Alaska and in an increasing number of other locations. A study by the Center for Disease Control and Prevention (CDC, 2002) indicated that the state of Alaska ranked highest in live births of infants with Fetal Alcohol Syndrome (FAS). The CDC study monitored the reported cases of FAS in newborns during 1995-1997 in Alaska, New York, Arizona, Wisconsin, and Colorado. Alaska had the highest reported rate of Fetal Alcohol Syndrome at 1.5 per 1,000 live births. Approximately 126 infants are born each year in Alaska who are affected by maternal alcohol use during pregnancy. The reported prevalence of FAS among Alaska Natives was the highest of all reported cases in Alaska and the other states (e.g., 5.6 per 1,000 live births).

The rise in the number of children with Fetal Alcohol Spectrum Disorders (FASD) in Alaska lead to the development of a five year project, funded by State of Alaska, Department of Health and Social Services, Office of Fetal Alcohol Syndrome aimed at providing diagnosis, surveillance, and conducting prevention activities across Alaska. This article presents findings from a 3-year evaluation of the state project designed to examine the education and community experiences of 5 students with FASD. The study includes the perceptions of family members and professionals.

In the past, with regard to individuals labeled FAS or FASD, research has centered narrowly around the areas of identification, incidence, prevalence, and diagnosis of the disorder of FAS while giving little emphasis on the individuals themselves, their experiences or needs. For example, research related to identification of the disorder emerged in the late 20th Century (Streissguth, 1997). Among the early identifiers of this condition was Dr. William Sullivan, who in 1899 published a study of 120 female "drunkards" at the Liverpool prison in Liverpool, England (Streissguth, 1997). His research indicated that the pregnancies of these women resulted in stillbirths and

infant deaths two and one half times more often than the sober female inmates. Although other researchers published work describing children prenatally exposed to alcohol (Fretz, 1931; Gooddard, 1912; Haggard & Jellinek, 1942; Ladrage, 1901; Pearson & Elderton, 1910; Roquette, 1957), it was not until 1968 that Dr. Paul Lemoine described the constellation of facial morphology that is described today as the face of FAS. Five years later Jones, Smith, Ulleland, and Streissguth (1973) published their seminal paper in *Lancet* that provided a comprehensive description of the constellation of physical features of FAS: "growth deficiency; and intellectual, motor, and adaptive behavior impairments." Their description closely matched earlier descriptions of children with FAS (Lemoines, Harousseau, Borteyru, & Meuet, 1968). As Streissguth (1997) later discovered, "The clinical confirmation was exhilarating; the 'FAS face' appeared to be unique to alcohol" (p. 40).

Building on the work of earlier medical and clinical researchers described above, Astley and Clarren (2000) conducted research at the University of Washington for more than 20 years related to establishing a clinical diagnostic code for Fetal Alcohol Syndrome. Currently their diagnostic process involves the identification of four primary diagnostic criteria: (1) Growth deficiencies that stunted prenatal and/or postnatal growth; (2) Permanent brain damage resulting in neurological abnormalities, delay in development, intellectual impairment, and learning/behavior disabilities; (3) Abnormal facial features including short eye opening, thin upper lip, and reduced or absent philtrum; and (4) Maternal alcohol use during pregnancy.

Alcohol-related neurological disorders, prenatal exposure to alcohol, fetal alcohol syndrome, static encephalopathy, and sentinel physical findings (alcohol exposure) are now considered to be part of the overarching category Fetal Alcohol Spectrum Disorders that describes the range of birth defects resulting from prenatal alcohol exposure. Fetal Alcohol Syndrome is only one of the disorders included under FASD. It is the level

of disorder as identified by a four-digit diagnostic code that makes clear the diagnosis of Fetal Alcohol Syndrome (Astley & Clarren, 2000). In this article, the authors use the term Fetal Alcohol Spectrum Disorders (FASD) to refer to the disorders as a spectrum and Fetal Alcohol Syndrome (FAS) when that disorder was clinically diagnosed or is the specific spectrum disorder being discussed.

Research in the area of identification, incidence, prevalence and diagnosis created a clinical and medical construct of FAS and FASD as defined and controlled by the medical and clinical system, rather than by the individuals themselves and their families. This type of research or orientation suggested places and people apart from the mainstream where individuals with FAS or FASD were referred if there was a concern of prenatal exposure to alcohol (e.g., diagnostic clinics). A growing area of literature in the field of disabilities and special education documents and discusses the broad range of experiences and supports which contribute to a sense of stability, belonging, and inclusion for individuals who experience disabilities (Bartholomew-Lorimer, 1993; Bogdan, 1992). This body of literature on inclusion, as yet not addressed in the research to date on FASD, is also quite relevant and important for students with FASD. This study investigates the school, home and community experiences of 5 students with FASD. All students participated in both segregated and inclusive schooling and community experiences.

The questions in this study were: (1) What are the unique characteristics, challenges and needs of students with FASD?; (2) How do the children themselves, their parents/caregivers and teachers experience FASD?; and (3) What lessons can be learned from the student descriptions about supporting the educational and life outcomes for students who experience FASD across the age range? What services and supports do these students benefit from?

This article describes the individual experiences of 5 students based on qualitative interviews and observations with the students, members of their families, and educational and medical professionals with whom they are involved. The experiences range from a sense of vulnerability and risk to a sense of stability, inclusion and belonging. We hope these descriptions will lead to an increase in sensitivity and awareness for educators and other practitioners and hence improve the lives of individuals who experience FASD. We hope that beyond receiving a diagnosis of FAS that students with FAS and FASD and their families will receive the supports and services that they require.

## Research Methods

Qualitative research methods were utilized (Bogdan & Biklen, 1998; Denzin, 1997; Denzin & Lincoln, 2000; Lincoln & Guba, 2000; Schwandt, 2000), including four data collection methods: (1) group and individual interviews with educators, diagnostic team members, family members, and students; (2) participant observation of students' classrooms, and various meetings between

professionals and between professionals and families; (3) collection and analysis of a wide range of relevant documents ranging from policy statements and newspaper articles on FASD to student Individual Education Programs, diagnostic team reports and day-to-day data collected on student performance; and (4) informal data that were volunteered through e-mail or telephone conversations, home visits conducted 3 times a year, or over lunch.

There were 5 key participants (Table 1), 4 boys and 1 girl, who ranged in age from 3-21 years old. Participants and associated contexts for this study were chosen in order to maximize cultural diversity, geographic location (e.g., city, village, town), and age and school level. Participants were recruited from the existing State Fetal Alcohol Syndrome (FAS) community based diagnostic teams to represent students of preschool, elementary, and secondary school age, and postsecondary age. Ultimately, participants were identified based on parent consent and interest in being involved in this study. Data including student ages at the start of the study, special education eligibility category, FAS diagnostic classification, school supports received and interviews conducted with school and community participants is illustrated in Table 1.

All formal interviews were taped and transcribed. Most observations resulted in summary or detailed field notes and informal discussions and observations were captured in either subsequent notes or memos. All data were collected by the first author and a research assistant; they included 135 formal interviews with a total of 71 participants across 3 years. Sixty-four interviews were repeat interviews. In other words, some participants, including parents, the students themselves, regular education teachers, special education teachers, and FAS navigators were interviewed more than once throughout the 3-year period (Table 1). In addition to the 135 interviews, approximately 400 hours of informal observations were completed. Each site was visited for two days three times a year (eighteen days per site across 5 sites for a total of 90 days of observation). Informal observations were conducted for approximately 5-10 hours on each visit across the five sites. These observations included a range of educational and home settings. The lead author observed in school hallways, cafeterias, gyms, students' regular and special education classrooms, childcare settings, and directly in the students' homes and communities. Some observations were formal, such as in the classrooms, and yielded extensive field notes. Other observations were informal in nature because of respect for confidentiality and privacy (e.g., participants' home, school hallways and cafeterias). During these informal observations the first author summarized observations in a journal at the end of the day. This article draws from all these data sources but relies most heavily on data collected through interviews. All together, over 3 years, we completed 135 interviews resulting in 3071 pages of typed, double spaced interviews. The extensive data collection was due to the nature of the state evaluation project and at the request of the funders.

Interviews were structured with an interview guide

Table 1  
*Participants*

Name	Age +	Student Descriptions	Participants Interviewed
Paul	22	Special Education Classification: Mental retardation; FAS Diagnosis: Static encephalopathy; FAS	Paul*; biological mother; foster parents*; FAS navigator*; diagnostic physician; diagnostic team; cousin; special education teacher*; special education teaching assistant; regular education teachers; principal; superintendent; special education director*
Alan	17	Special Education Classification: Emotional disturbance; FAS Diagnosis: Static encephalopathy, Sentinel physical findings	Alan*; foster parents*; diagnostic team; special education teacher*; regular education teachers (3)*; principal*; special education director; special education coordinator; FAS navigator*
Oscar	15	FAS Diagnosis: Other health impaired; FAS Diagnosis: Neurobehavioral disorders, Alcohol exposed	Oscar*; adopted father*; principal (2)*; superintendent; special education director; 2 police officers; special education teacher (2)*; regular education teachers (7)*; FAS navigator (3)*; diagnostic psychologist; special education teaching assistant (2)*; school counselor*; behavioral health counselor; behavioral health community worker; residential treatment facility teachers/workers* (3); residential treatment facility counselor*
Ellie	11	FAS Diagnosis: Other health impaired; FAS Diagnosis: Static encephalopathy, Sentinel physical findings, Alcohol exposed	Ellie; special education teacher*; regular education teacher*; principal (2)*; grandmother*; biological mother; FAS navigator*; FAS community workers
Adam	6	FAS Diagnosis: Speech impaired; FAS Diagnosis: Prenatal drug exposed, Neuro behavioral disorder, Alcohol exposed	Foster parent*, FAS navigator; child care teacher * (3); special education director; regular education teacher*; FAS navigator*; special education teacher (2)*
			*repeated interviews (some occurred up to 3 times a year over 3 years)+ +ages represent age at the end of the 3 year study

that allowed participants to talk freely about their perceptions and concerns regarding working with, parenting, or being a person with a FASD. The interview guide included questions addressing a range of topics including (1) relationships and experiences with the student participants; and (2) perceptions regarding the characteristics, challenges, and needed supports of FASD students and their families. Most interviews lasted an hour, some up to two.

All data were analyzed inductively, reflective of interpretivist research (Bogdan & Biklen, 1998; Maxwell, 1996). All interviews were read and coded at first using a large number of discrete codes and later combining codes to create larger categories. For example, the codes "behavior," "lying," "running away," "stealing," "manipulative" later were recoded as "characteristics of students with FASD."

The program HyperQual 3 (Padilla, 1999), a text-sorting program designed to assist in qualitative data

analysis, assisted in sorting and combing codes and generate 20 code-specific reports. These 20 code-specific reports included: "characteristics of students with FASD," "challenges," "strengths," "home life," "history," "teachers' perceptions," "parents' perceptions," and "student voices." At the same time, data were read and reread and major messages or "themes" were identified. Some initial codes related to characteristics and challenges, for example, were later reported in terms of the students' vulnerabilities, and emerged as ways of describing the unique experiences of living with FASD discussed in this article.

The credibility and authenticity of the study were enhanced by several strategies suggested by Lincoln and Guba (1985). The strategies included: (1) the lead author's prolonged engagement in the field (multiple contacts with participants over a 3 year period); (2) use of observer comments and field notes (Taylor & Bogdan, 1984); and (3) triangulation of data.

## Paul, Alan, Oscar, Ellie, and Adam: The Person Behind the Face of FASD

This section provides an introduction to the students who were the focus of this study, their families, and school and community settings. The descriptions of the five students with FASD are categorized along three dimensions: (a) the person behind the face of FASD including individual characteristics; (b) family and community life including descriptions of the students' early and present home life; family members, and community of residence; and (c) school life including type of classroom, educational experiences and special education supports received.

### *The Person Behind the Face of FASD*

When the study began Adam was 3, Ellie was 9, Oscar was 12, Alan was 15 and Paul was 19 years old. Four of the five students have FASD and one (Paul) has FAS. Four of the five were evaluated by the Alaska FAS diagnostic clinics (Alan, Oscar, Ellie and Adam). Paul, now twenty-two, received the diagnosis of FAS when he was 5 years old.

Parents and teachers of the five students describe the students as "small for their age." Alan in 11<sup>th</sup> grade and Oscar in 9<sup>th</sup> grade both look at "least 2 years younger than their age." Oscar's adopted father Richard worries that Oscar will be taken advantage of by others, because of his size and also because of his "mouth." Richard shares that Oscar "talks big" and he "doesn't know his limits." Some participants felt that some of the students had the "face of FAS." Meaning that they had "small heads and eyes," "thin upper lips," or "were small for their age." Other participants said that the student looked "normal" or "just like anyone else in my class."

All of the students are described as "very active," "poor decision makers," "lacking in judgment skills," and "distractible" by their parents and teachers. Paul, Alan, and Oscar's parents have used the words "manipulative," "lying," "stealing," and "running away" to characterize some of their actions. Richard, Oscar's adopted father described one episode where Oscar ran away for 3 days. Richard shares that "he drank and used marijuana. He hid out under the Fish and Game Building with two other boys for 3 days. They left to steal food from the store to keep them going."

### *Family and Community Life*

Four of the five students (Alan, Oscar, Ellie and Adam) lived in rural villages or towns in Alaska. The population of these four towns/villages ranged from 554-7,900 residents. Three of the five students (Paul, Oscar, and Ellie) lived in native Alaskan villages (e.g., Athabascan, Yupik and Tlingit). Several of the communities have both school and community poverty levels that are below the national average for the United States.

Four of the five participants (Paul, Alan, Oscar and Adam) have lived with foster or adopted families most of their lives. Paul lived with a non-native foster family for 13 years. Alan, the only Caucasian in the study, was

adopted by a family in the lower 48 before they moved to Alaska. Oscar was adopted by his mother's boyfriend after she died. Adam was adopted by Lillian when he was 3 years old. Ellie, the only girl in the study, lives with her biological grandmother.

All five participants have experienced early trauma. The birth histories of all five participants involve reported consumption of alcohol by their biological mothers. Paul's mother, whom he stays in contact with, has episodes of drinking and sobriety. Paul has lived with his mother off and on after he graduated from school when she was sober. Alan's mother, who was a teenager when she gave birth to Alan, has died of "alcohol related issues." Oscar's mother died when he was five. Richard, Oscar's adopted father, tells us that they drank heavily when Oscar was young. Richard has been sober for 10 years. Ellie's grandmother allows her daughter (Ellie's mother) to see Ellie as the grandmother puts it, "when she is sober." Adam's biological mother died from of alcohol abuse when he was 2 years old.

Four of the five students are Alaskan Native; one student is Caucasian (Alan). One student lives in a major city (Adam). Two of the students (Paul and Oscar) grew up living a subsistence lifestyle. They learned to hunt and fish and mush dogs. Paul, raised by two older Caucasian foster parents, learned to hunt caribou, moose, and rabbit, and fish for salmon in the summer. He knows how to "take care of himself in the woods." Paul shares that "I'll be busy all the rest of the summer cleaning fish, cutting moose probably and picking berries." Oscar goes hunting and fishing with his adopted father Richard every year. His father is a dog musher and Oscar knows how to take care of the dogs. In fact, on one visit the lead author made to Oscar's home in rural Alaska in the winter, Oscar harnessed a team of 6 dogs and took them for a run in -10 degrees. Ellie has lived with her native grandmother and has learned many native skills such as cooking and berry picking from her. Paul, Oscar, and Ellie showed pride in their heritage and their way of life. They describe their love of their village and community. Once during a weekly visit by the lead author to the residential treatment facility, where Oscar was placed, he shared: "I want to go home. My home is in the village. I miss my family."

Three of the five students have used alcohol and/or marijuana. Paul tested positive for marijuana on a job he had when he graduated from high school. He was fired. When Richard discovered that Oscar had used alcohol and marijuana in the 7<sup>th</sup> grade he decided to enroll him in a residential treatment facility. Alan's adopted family suspect that he has used alcohol. Teachers and parents voice their concern for the students' potential misuse of alcohol and drugs because of their biological parent's history and because of their vulnerability to peer pressure. During the last interview that we conducted with Paul he tells us "I'm doing pretty good. I've been sober for almost 2 and one half months and a week now. And, I'm reading the Bible and going to church." We ask him how that is going and he says:

... in [in the city] it is harder for me. It is too wild [in the city]. I don't think it is a place for me to be. Talk about drinking, you go down the road there's a liquor store. I don't want to do that. It costs 2 bucks to get gas up here [in the village]; so I just stay sober better here [in the village].

### *School Life*

Participants in this study attended schools in which the reported scores for tenth-graders taking the high school qualifying examination in 2003 ranged from 42-50% proficient in writing, 40-59% proficient in math, and 53-73% proficient in reading. The per pupil cost of education also varied across the 5 school districts from \$3,000 to \$10,000.

All students attended their home schools and were enrolled in general education classes with supports. Four of the five the students were referred for special education at some point in the 3 year study. Paul was eligible to receive special education services under the category of "mental retardation" before the study began. He received resource room support for half of this school day and was integrated into English, shop, and PE classes. In shop he learned to make a native kayak with assistance. Oscar was referred for special education services at the end of 6<sup>th</sup> grade. He was found eligible under the category of "other health impaired" and received resource room support for math and reading. Alan was eligible under the category of "emotional disturbance" in the 9<sup>th</sup> grade. He received resource room support in the area of English, math, and writing. Ellie was referred for special education in the 3<sup>rd</sup> grade and found eligible under the category "other health impaired." Adam received preschool special education services under the category of "speech impairment."

Two of the five students spent time in a residential treatment facility. Alan's adopted parents sent him to an out of state facility because of his "behavior." The behavior that was of concern to his parents included "lying, stealing and not be able to trust him." He remained in the out-of-state placement for 2 years and was not a part of the study after year one of the study. Oscar's father sent Oscar first to a treatment program in the village and then to a larger treatment facility in a large city in Alaska because of his "running away, alcohol and marijuana use, and stealing." At the time of this writing Oscar, age 15, is in prison. Although Richard shared the circumstances with the lead author, he did not feel comfortable having the reasons for the incarceration published in this article.

### **Discussion: Student Experiences and Perspectives of Families and Professionals on FASD**

Existing as it does at the intersection of rights-based mandates, child health, social welfare, and standards-based education, the concerns of FASD transcend the narrow disciplinary niche of special education. The findings of this study suggest that students who

experience FASD are first and foremost human beings with interests and gifts. As the field of FASD develops, it will be important to keep a focus on the person behind the disability. In many the interviews with the diagnostic team members the focus was on the disorder of FASD and the inherent complications resulting from the damage alcohol inflicted on the brain. In Gallagher's (1998) critique of the science of special education, she noted the "relegation of moral discourse to the periphery of the field and sought a return to the finest accomplishment of special education, that is, advocacy for the human dignity and civil rights of individuals with exceptionality" (p. 500). The findings of this study certainly underline this sentiment and illustrate that attention be given by educators, policy makers, and politicians, to the children themselves who are being diagnosed with a FASD. Here we briefly explore three themes that have emerged during this study.

### *Fleeting Success and Competence*

*Fleeting success and competence in the outdoors.* For several students in our study success and competence varied from context to context. Many of the students revealed high levels of adaptive skills such as competence in the out-of-doors. For example, Oscar is Richard's "right-hand man." Oscar's father and uncle have a dog team and mush dogs competitively in their region of the state. Oscar's father describes the type of things that he does with his son: "We go to fish camp each summer, hunt, and in the winter we dog-mush." At fish camp the family members catch and process salmon. In the winter, Oscar helps with the dogs. Richard describes Oscar as a "skilled native boy" but also struggles with his "son's running away, stealing 4 wheelers, and getting into trouble."

Paul shared that the "foster father and mother who [he] lived with from the time he was 8 until he was 17 taught him to hunt, fish, and live off the land." In fact, Paul's cousin shared in an interview that if she were in the wild "she would want to be with Paul." She says he is very skilled and capable and would take care of her. All the male students in this study were described by their caregivers as "active." Even 3 year old Adam enjoyed climbing and running. His childcare teacher shared that this interest of his is not always safe. "You see, one day he climbed over the fence on our playground into the street."

Ellie, being slightly overweight for her height, loved the outdoors and often went berry picking with her grandmother. She did not like organized sports or outdoor games. As she said "I'm not that good at it."

*Fleeting success and competence in school.* School life has been a mixture of successes and challenges for the students in this study. All 5 students receive support from special education teachers and have Individual Education Programs (IEPs). Although Paul graduated in 2002, he had been in special education resource classrooms for most of his education. When he was six he was found eligible for special education services under the category of mental retardation. Paul's teacher says he is "unique"

because he “stuck it out in high school and graduated.” She noted that many other students without disabilities in her area drop out of school. The teacher went on to describe Paul as a “very happy, pleasant, and hard-working young man.” Despite this praise, Paul did not pass the high school qualifying exam.

Oscar became eligible for special education at the end of 6<sup>th</sup> grade, receiving a classification of other health impaired. Oscar attended general education classes at his regional high school and also receives counseling services from the school social worker and from a community behavioral health specialist. These support services provide him with “someone to talk to.” Both therapists are working on supporting Oscar to make good decisions in school and in his choice of friends. Oscar did not pass the benchmark tests in math, reading and writing at two different points during the 3 years of this study.

Ellie is another student who was found eligible under the IDEA category other health impaired (OHI). Her teacher shared that the diagnostic team coordinator, the psychologist, and the physician attended the IEP meeting and it was the physician who advocated for Ellie to be classified with a FASD and receive services under the classification of OHI. Ellie enjoys school, she loves her teacher, and her favorite subject is computer class. Ellie, like Oscar, did not pass the benchmark tests during the three years of this study.

Adam, with a classification of speech impaired, attended a preschool special education program in the morning and went to a childcare center in the afternoon. His special education preschool class consisted of seven boys. Adam, as Jen (his teacher), describes him, is “very active, very busy, and generally does not spend more than a minute on one thing.” She works to “redirect” him and to encourage “social interactions with his peers.” In the second year, his adopted mother had to limit his schooling to only the childcare setting since he was not able to attend the morning preschool special education program. Lillian, Adam’s adopted mother, shares that between the long bus ride from his childcare setting to the preschool, and not having the chance to eat lunch, he “just fell apart” in the afternoon classroom. She tried to get him transferred to the morning preschool special education classroom, but, was told “there were no openings.” In the third year of the study Adam was integrated into the local kindergarten classroom. Although he receives special education support his teacher feels that “it is not enough and she is encouraging full day special education services.”

All the students in this study were found to be in various ways in need of supports in school, and in the community as well as their home environments. The community supports that were viewed by the students’ parents as beneficial were: “counseling, behavioral supports, and after school activities.” The school supports that were viewed as beneficial by the parents were: “special education services, counseling, one on one tutors, and caring teachers.”

For the most part, the teachers were hopeful for these students. They describe the future for students who experience a FASD in one of two ways. Some, like Jen

(Adam’s teacher), Ruth (Ellie’s teacher), and William (Oscar’s vice principal) are optimistic about the future. Other teachers interviewed voiced their concerns about Oscar, and Paul as “getting in trouble with the law,” “stealing,” “running away,” and “petty larceny.” They felt strongly about the need for their students with a FASD to receive lifelong supports both in the community and in school.

## *Vulnerable Students and Families*

*Vulnerability: Death in the Family.* Being vulnerable characterizes the lives of all five students in this study and this vulnerability manifests itself in various ways. During the 3 years of this study several of the students experienced deaths in their immediate or extended families due to alcohol abuse. For instance, Adam’s birth mother died of liver damage due to alcohol after a long illness. Oscar and Alan’s birth mothers also died as a result of alcohol abuse. Ellie’s brother died at birth. Paul’s 29-year-old sister died during the second year of the study, as Paul puts it, “from drinking too much.” On one home visit the lead author made to Paul’s home in rural Alaska, he shared: “it makes me real sad. She’s gone. I will miss her. For me, I don’t drink anymore, it’s been 2 months now for me [since I drank].”

*Vulnerability: Unstable Home Life.* Beyond experiencing the deaths of their parents or siblings, the students in this study experienced the vulnerability and inconsistency in home life. Paul has been in various foster care placements. Ellie, who lives with her grandmother, sees her natural birth mother only when she is not drinking. At only 3 years old, Adam experienced the move from the world of social-service foster care to the home of a loving adoptive mother into childcare settings and special education. Alan and Oscar have spent time in residential treatment facilities. All have learned to live with many changes and transitions in their lives. Changes that most of us would find incredibly challenging and that require enormous preparation, these students seem to endure again and again. Changes in environments including homes and schools, and changes in caregivers and other people in their lives, are commonplace.

*Vulnerability: No supports after school.* Finally, children with FASD are vulnerable in some unique ways once schooling is finished. There are no entitlements for continuing supports and services once formal public schooling has ended. Most students with FASD are not eligible for assistance through the mental health or developmental disabilities organizations. For students with a FASD like those described here, there is a critical need for support services that many are not currently receiving. Without the supports, such as counseling, respite care for primary care providers, and behavioral support services for families students with FASD are vulnerable for foster care parents or adopted parents giving up their rights, use of alcohol or drugs, and placement in residential treatment facilities. It can be said that children with other disabilities experience the same outcomes (e.g., lack of services outside of school, lapses in services upon graduation, etc.). For children with FASD



the outcomes often move towards a critical and crisis level as the following section illustrates.

### *Anticipated Trajectories*

*Anticipated trajectory: Petty crimes, drug and alcohol use, time in residential treatment centers and prison.* The interviews and observations conducted over the course of three years produced various explanations and interpretations regarding the students' behaviors and those of students with FASD in general which give us reason to be concerned. Clearly, these 5 students experience challenges, in school and in other community settings. One interpretation is that these challenges can be addressed—students can be helped to learn, acquire skills, and develop strategies for managing their challenges like many other students with learning needs, whether labeled or not. Another interpretation, however, is that students with a FASD are somehow “doomed” to fail—they will abuse alcohol and other substances and they will “get into trouble” in one way or another. The acquisition of the diagnosis seems to carry with it a sense of an inevitable trajectory for many of the adults in their lives, both family members and professionals. The trajectory is one that is characterized by behaviors such as lying, stealing, “being sneaky” and “getting into trouble with the law.”

Of course, it's hard to connect such characteristics directly to the medical disorder, but the social construction of what it means to have an alcohol related disability may be a combination of perceptions about the disorder itself, and the reality of the individuals' lives and behaviors. A teaching assistant, who lived in the same village as Oscar when he was younger, told us that “he huffed gasoline from snowmobiles when he was 5.” In the 6<sup>th</sup> grade, Oscar and a friend siphoned gasoline from a boat in the village and set a shed on fire. Oscar's father has had the police come to his house to talk with Oscar about the potential consequences (e.g., jail) of his actions. Oscar's father was not sure if listening to the policeman describe how his “behaviors could land him in jail, has helped him.” Despite his father's interventions on his behalf, in 9<sup>th</sup> grade Oscar had spent 2 months in jail.

Paul, too, has engaged in “at-risk” behavior. His high school principal described two examples: “He had a job at the local restaurant, but couldn't keep his hands off the tips,” and “he has been drinking, crawls out of his bedroom window and gets drunk with his friends.” According to the elder who Paul works for, “he's gone back to drinking. When he goes back to the village, I am worried about him.”

During several interviews, the lead author was told by one administrator and two local law enforcement officers in a rural community “more that 50% of the men in the prison we think have FAS.” Another interviewee, a FAS navigator, shared that she felt many of the homeless men on the streets “probably have FAS.”

Abuse of alcohol, getting in trouble with the law, and incarceration are potential realities for the students in who were a part of this study. On the first author's last visit with Oscar he shared that uncle and step brother were currently in jail.

### *Social and Cultural Stigma*

Is there is a social and cultural stigma to the diagnosis of FAS or FASD? Individual diagnostic teams conducting FAS clinics in the communities where the 5 participants lived reported data indicating that Alaska Native children between the ages of 1 and 21 who have a diagnosis of FASD accounted for 62% (Paul's community), 21% (Alan's community), and 95% (Oscar's community) of all reported diagnoses. Of course, these data may not tell the whole story. Do other ethnic groups request clinical diagnosis less frequently? Might it be suspected (in non native families) less frequently by school and medical professionals? Or, is the Alaskan Native community paying more attention to this disability as the director of the state FAS project believes? Certainly, the interplay between a service orientation and the kind of condemnation elicited by some behaviors such as alcohol and substance abuse makes it difficult for students with a FASD to escape both social, and perhaps cultural stigma.

### *Conclusion*

In order to support the person behind the face of FAS, an emphasis needs to be placed on fostering competence and a sense of stability and belonging. We have found that this has not regularly occurred as a result of the student's obtaining a diagnosis. Receiving a diagnosis did not automatically lead to increased or better supports and services for the students or their families in this study.

Beyond diagnosing the disorder of FAS or FASD, teachers, physicians, and agencies should focus on cultivating support services and systems that would result a sense of competence and stability in students with a FASD. Based on the findings of this study we offer some strategies for service providers and other allies to help increase students' positive school, community, and life experiences.

### *Supporting Competence Through a Sense of Stability and Belonging*

Participants in this study experienced significant disruptions in their homes and schools. In some cases, such as Alan and Adam, students have lived with multiple foster families. In addition, their foster or adopted families were given very limited supports.

Lillian, Adam's adopted mother, had to take time off work when her son was expelled from four child care centers in the third year of the study. Adam's behaviors including running around and needing their “constant attention” caused the child care staff to feel overwhelmed. They expressed a need to have a full time teaching assistant, something that the special education program was unable to provide. Oscar's father described his concerns over his son's whereabouts after school. He, as well as other families, expressed the need for organized after school programs that would teach their children social skills and appropriate behaviors. All family members described that they received limited or no hours of respite care. Their sense of isolation was increased by the fact that

their ability to "live a normal life" was impacted by their child with FASD.

A sense of stability and belonging can be promoted by assisting students and families to receive services such as respite, counseling, and social skills training in their homes and communities. Such services may involve counseling for the student and/or family, behavior consultation in the home, parent support and training, and respite care.

### *Avoiding Stigmatization*

Participants in this study shared issues related to the number of children from underrepresented groups, including Alaska Natives, who might represent a larger than average number of children identified as FASD. In other words, individuals of Alaska Native ethnicity are being referred for a diagnosis of FASD at a higher rate than other ethnic groups (Office of FAS Data Reporting Form, 2002). Diagnostic team members interviewed shared that they believe that there are children with FAS in other ethnic groups (e.g., Caucasian), but that those groups are not necessarily being referred to the diagnostic teams. In other words, as one FAS team coordinator shared: "FAS is an equal-opportunity disability." When asked to explain what she meant by this phrase she shared: "drinking during pregnancy occurs across ethnic, religious, and socio economic levels."

Political, cultural, and societal contexts, including economic issues related to child poverty, per-pupil cost for education, low performance on standards-based examinations, and the high percentage of Alaska Native children diagnosed with a FASD represent the larger context in which the 5 participants in this study live. Further research into this phenomenon will reveal efforts teachers and agencies are making to respond to the

overrepresentation of Alaska Natives being diagnosed with FAS. Furthermore, the efforts undertaken to support foster or adopted families who parent children with FASD should be investigated.

The findings in this article represent the reality of these 5 individuals' lives as depicted by interviews conducted with professionals, parents and the students themselves, in addition to three years of observations in the field. We acknowledge that other individuals with FASD may not be "seen" in these students' descriptions; but we believe many aspects of these 5 individuals' lives will resonate to the lives of others who carry the label of FASD. These students' descriptions raise other questions that need to be explored. For example, will the trajectory of an individual's life who has FASD be one of experiencing multiple foster or adopted families; inconsistency in support systems, and ultimately involvement with the criminal justice system? We believe that more information is needed about children and young adults who have FASD. Highlighting successful students as well as students' whose lives are challenged and erratic would provide important knowledge to the field. Understanding supportive factors that help students with alcohol related disabilities experience positive educational outcomes and life experiences is needed.

After analyzing the data, a pressing question continues to concern us. How can children with a FASD be supported such that they may live healthy and fulfilled lives? As we learn more about the usefulness of this diagnosis and the spectrum disorder and about the strategies that facilitate learning, it is important that we do not lose sight of the important lessons learned from these 5 students and the human beings behind the "face of FAS."

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