

# On, Yet Under, the Radar: Students With Fetal Alcohol Spectrum Disorder

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**ABSTRACT:** This 3-year qualitative study investigated the diagnostic process and the experiences of professionals and families associated with 5 Alaskan students with Fetal Alcohol Spectrum Disorder (FASD). The data revealed (a) an increase in public awareness, but limited provision of services for children with FASD and their families; (b) the use of differentiated instruction by experienced teachers, but beginning teachers who experienced frustration and were less likely to adapt instruction; and (c) the pervasive impact of challenging behaviors, but the limited support provided to families. The results offer insights into FASD and suggest implications for coordinated educational services and family supports.

A generation has passed since Lemoine, Harousseau, Borteyrun, and Menuet (1968) established that women who drank heavily while pregnant gave birth to underweight infants with distinct facial features, cognitive delays, and challenging behaviors (Golden, 2005). During the ensuing years much of the research and policy efforts regarding Fetal Alcohol Syndrome (FAS) have focused on the issues of incidence, prevalence, prevention, and diagnosis (Astley & Clarren, 1997, 2000; Clarren & Astley, 1997; Clarren & Smith, 1978; Cordero, Floyd, Martin, Davis, & Hymbaugh, 1994; Dehaene, 1995; Dehaene et al., 1991; Jones, 1988; Jones & Smith, 1973; Lemoine & Lemoine, 1992; May, Hymbaugh,

Aase, & Samet, 1983; National Institute on Alcohol Abuse and Alcoholism, 1987); investigations into attitudes toward alcohol consumption in pregnant women (Halmesmaki, 1988; Streissguth, 1997); perceptions by medical personnel of the impact of maternal consumption on the developing fetus (Dufour, Williams, Campbell, & Aitken, 1994); and the effects of alcohol on the brain of the fetus (Aronson, 1984).

Astley and Clarren (2000) established a clinical diagnostic code for FAS, identifying four primary criteria: (1) growth deficiencies that stunt 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 (Astley & Clarren, 2000).

Fetal Alcohol Syndrome is a clinical diagnosis; Fetal Alcohol Spectrum Disorder (FASD) is not (Astley & Clarren, 2000). FASD describes the range of birth defects (e.g., alcohol-related neurological disorders, prenatal exposure to alcohol, FAS, static encephalopathy, and sentinel physical findings/alcohol exposure) resulting from prenatal alcohol exposure; FAS describes one of the disorders within the spectrum. In this study, FASD is used to refer to the spectrum of disorders, and FAS refers to (a) the official name of the Alaska project or activities conducted within the project, (b) research studies reporting specific findings on children with FAS, or (c) the specific disorder of FAS.

Children with FASD are described as having (a) facial deformities and severe neurobehavioral impairments, (b) impaired cognitive functioning, (c) problems following directions and understanding the consequences of their actions, (d) poor memory and judgment skills, (e) difficulties respecting social boundaries and rules, (f) delays in communication, (g) variable performance in school, and (h) challenging behaviors (Abkarian, 1992; Burgess & Streissguth, 1990; Coggins, Friet, & Morgan, 1998; Kleinfeld & Wescott, 1993; National Research Council, 2001; Ryan & Ferguson, 2006; Streissguth, 1997; Streissguth, Barr, Kogan, & Bookstein, 1996; Streissguth, Clarren, & Jones, 1985; Streissguth & Kanter, 1997; Timler & Olswang, 2001). The consequences of prenatal exposure to alcohol appear to persist throughout life (Connor & Streissguth, 1996; Institute of Medicine, 1996) and to require lifelong supports.

Despite the attention given to diagnosing FAS, and describing the children's characteristics, there has been almost no systematic research on the educational needs of students with FASD or on best educational strategies (Kleinfeld & Wescott, 1993; Streissguth et al., 1991). In one notable investigation, Streissguth et al. (1996) conducted life history interviews with parents and caregivers of 415 people with FAS to identify secondary disabilities. The data indicated that 61% of those 12 years and older and 14% of those ages 6–11 had disruptive school experiences, defined

as being suspended or expelled from school, or dropping out. Streissguth and colleagues (2004) identified risk and protective factors for individuals with FASD noting that receiving a diagnosis early and living in a stable home environment increased the odds of escaping negative outcomes such as school expulsions and prison.

Gorman (1995) interviewed 20 individuals with FAS between the ages of 15 and 20, to learn more about their perceptions of school. Participants reported having disruptive school experiences; 9 had been suspended, 6 had dropped out, and 1 had been expelled. The 4 individuals who did not report disruptive school experiences expressed the feeling that "someone at school had really cared about them" (Streissguth, 1997, p. 209).

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These studies provided an initial framework for research efforts focused on understanding the experience of FASD from the individual's perspective.

The current qualitative research study examined the process of diagnosis and educational and community support for 5 students with FASD. It builds upon the work of Streissguth et al. (1996), Streissguth et al. (2004), and Gorman (1995) to provide a deeper understanding of the experiences of students with FASD, their families, and professionals.

## METHOD

### PARTICIPANTS AND SETTING

*Background.* The Centers for Disease Control (CDC) funded a 4-year project for the Alaska Department of Health and Social Services, Alaska Office of FAS (AOFAS), to develop, implement, and evaluate FAS diagnostic clinics in 14 rural and urban settings across Alaska. Local diagnostic teams were responsible for receiving referrals, conducting FAS diagnostic clinics, producing diag-

nostic reports, and conducting limited support services for families.

CDC required AOFAS to obtain an outside evaluation of the diagnostic team process. The current study is one of three undertaken; the others were a study of women at risk (Hughes & Morse, 2002) and a study of the diagnostic teams, including their interdisciplinary evaluations (Johnson & Brem, 2004). This article presents findings from the last 3 years of the 4-year project. The data presented in this article represent a subset of a larger data set (Ryan & Ferguson, 2006).

*Participants.* Participants were identified by the parent navigator of the newly established state FAS diagnostic teams to represent students from preschool, elementary, secondary, and postsecondary settings. The participants were additionally chosen in order to represent a geographic cross section of Alaska.

The 71 individuals interviewed included the 5 focus student participants; their biological, adoptive, and foster parents, and other extended family members; parent navigators (parents whose role it is to advocate and support a family through the diagnostic process); diagnostic team members; child-care workers, special and general educators, principals, and special education directors; superintendents; psychologists, social workers and counselors; police officers; physicians; residential treatment center staff; and behavioral health counselors.

The 5 key participants ranged from 3 to 19 years old (see Table 1). The key participants were of diverse backgrounds, and included 1 Athabascan Alaska Native, 1 Athabascan/African American, 1 Tlingit Alaska Native, 1 Yupik Alaska Native, and 1 Caucasian student. Of the 5 students with FASD, 1 student had been diagnosed with FAS; overall diagnostic classifications included FAS, static encephalopathy, sentinel physical findings, neurobehavioral disorders, and alcohol-exposed.

Special education eligibility categories included other health impaired, mental retardation, emotional disturbance, and speech impaired. Four of the 5 students were described as having behavioral and mental health challenges.

*Settings.* Four of the 5 participants (Paul, Alan, Oscar, Ellie) lived in rural villages or towns

with populations ranging from 554 to 7,900; Paul, Oscar, and Ellie lived in Native Alaskan villages (i.e., Athabascan, Yupik, and Tlingit). Adam lived in a city. Four of the 5 participants' communities were below the national poverty level.

#### DATA COLLECTION

The lead author established rapport with the 5 students, their families, and their teachers in the context of three 2-day site visits a year across the 3 years of the project (total of 90 days). The lead author conducted 85% of the interviews and observations across the 3 years. A trained research assistant conducted the remaining interviews and observations.

Data collection included (a) semistructured interviews; (b) observing students' classrooms, and various meetings between professionals and between professionals and families; (c) analyzing documents ranging from policy statements to student individual education programs (IEPs) and day-to-day student performance data; and (d) informal e-mail or telephone conversations.

The initial interview guide developed in conjunction with AOFAS contained open-ended prompts for questions about (a) the process of diagnosis, education, and community support for students and families; (b) participant perspectives on the provision of services for students with FASD; and (c) the perspective of the families who received these services.

The second or subsequent set of interviews was conducted three times each year. Guides developed for these later interviews included the same topic areas, but also questions concerning changes in the child and family since the previous visit. Participants chose the interview settings, which included living rooms in families' homes, classrooms, administrative or counseling offices, coffeehouses or restaurants, and participants' cars. Interviews lasted from 45 minutes to 2 hours and were audiotaped for later transcription and coding analysis. Participants who were interviewed more than once during the 3 years of the study are indicated with an asterisk in Table 1.

*Observations.* The study included 400 hours of observation across the 5 sites. Observations initially focused on the 5 students, who were observed in their homes (e.g., eating dinner,

TABLE 1

*Participant Information*

<i>Name of Student</i>	<i>Age<sup>a</sup></i>	<i>SPED Category &amp; FAS Diagnosis Category</i>	<i>Participants Interviewed</i>
Paul	19	Mental retardation; Static encephalopathy, FAS	Paul*, biological and foster parents*, FAS navigator*, physician, diagnostic team, special education teacher*, general education teacher*, principal, superintendent, special education director
Alan	15	Emotional disturbance; Static encephalopathy, Sentinel physical findings, Alcohol exposed	Alan*, foster parents*, diagnostic team, special education teacher*, general education teacher *(3), principal*, special education director, special education coordinator, FAS navigator*
Oscar	13	Other health impaired; Neurobehavioral disorders, Alcohol exposed	Oscar*, adopted father*, principal (2), superintendent, special education teacher *(2), police officer (2), general education teacher (7)*, FAS navigator (3)*, diagnostic psychologist, special education assistant (2)*, counselors*, behavioral health counselor, behavioral health community worker, residential treatment facility teachers/workers (3)*, residential treatment facility
Ellie	9	Other health impaired; Static encephalopathy, Alcohol exposed	Ellie, special education teacher*, general education teacher*, principal* (2), grandmother*, biological mother, FAS navigator*, FAS community worker
Adam	3	Speech impaired; Prenatal drug exposed, Neuro behavioral disorder, Alcohol exposed	Foster mother*, FAS navigator, child-care teacher*(3), special education director, general education teacher*, FAS navigator*, special education teacher (2)

\*Repeated interviews (some occurred up to 3 times a year over 3 years).

<sup>a</sup>Ages represent age at the start of the 3-year study.

working with dog teams, watching TV, playing with siblings), in school or treatment facilities (e.g., in classrooms, hallways, labs, cafeterias, gymnasiums, school yards, special education resource rooms, and child-care classrooms), and during activities (e.g., large-group lessons, small-group lessons, one-on-one instruction, benchmark testing, independent work, transitions between classes). Other variables became part of the observation (e.g., interactions between teachers and students, and interactions between children and their families, activities occurring in the school, differentiated instruction, and curricula modified by the teachers).

During observations in the classroom, we attempted to minimize intrusion into the normal operation of the classroom. In most cases, the ob-

server sat quietly in the back of the room and recorded notes on a laptop computer, with minimal direct interaction with students. At other times, the researcher walked around the classroom and interacted with the focus student as well as with other students. We also conducted and recorded field observations (home visits, treatment facility visits, parent or student employment visits, and mountain hikes and shopping).

*Permanent Products and Informal Data.* We collected documents such as e-mails from participants (e.g., parents, special education teachers, special education directors, FAS coordinators, FAS parent navigators), student IEPs, FAS diagnostic team reports, school assignments, school newsletters, and newspaper articles pertaining to

FAS or alcohol use in the particular village or town.

This article draws from all these data sources but relies most heavily on data collected through interviews. Over 3 years, we completed 135 interviews with 71 participants, resulting in 3,116 pages of typed, double-spaced interview reports. The volume of data collection was due to the nature of the state evaluation project.

#### DATA ANALYSIS

The current study used categorical coding (Bogdan & Biklen, 1998; Denzin & Lincoln, 2000; Miles & Huberman, 1994; Wolcott, 1994) and contextual comparison analysis (Maxwell, 1996) to analyze the interviews, as well as HyperQual 3 (Padilla, 1999), a text-sorting computer program. The lead author conducted the initial and final coding and analysis of the interviews; the second author read all interviews, reviewed the coding system, and discussed confirmability (the degree to which the themes were grounded in the data) and dependability of the data (Kasahara & Turnbull, 2005; Lincoln & Guba, 1985). The categories shown in Table 2 were developed and refined over the course of the study to organize and merge categories in coherent connections. These subcategories enabled us to consider (a) how events occurred across the years and across the participants, (b) how the properties of the categories related to the various participants' views (family members', educators', and diagnostic team members'), and (c) what specific events assisted or interfered with the students' and families' lives.

Four major codes emerged during the open-ended coding process, and approximately 15 subcategories during second-level coding. Through the process of constant comparison and inductive reasoning (Bogdan and Biklen, 1998; Denzin & Lincoln, 2000; Lincoln & Guba, 2000; Miles and Huberman, 1994) we analyzed participant responses, and arrived at three themes (Table 2): (a) "On, Yet Under, the Radar"; (b) "I Don't Do Anything Differently With Oscar", and (c) "If I Had Known Then What I Know Now."

*Authenticity and Credibility.* This study included prolonged engagement in the field, triangulation of data, and external checks on the data analysis by "peer debriefing" of interviews and

field notes to ensure authenticity and credibility (Bogdan & Biklen, 1998; Lincoln & Guba, 1985, 2000; Wolcott, 1994).

Each participant was given a copy of his/her transcribed interview and of the evaluation project draft report, which outlined major themes and findings from the data. Participants were asked to respond in writing to two questions: (a) whether their privacy was maintained and (b) whether the themes and findings were consistent with their own experiences. The participants provided their answers in writing, and follow-up phone conversations resolved any unclear written answers. These responses were incorporated into the findings.

#### FINDINGS

Three themes emerged that represented the perspectives of the participants regarding the diagnostic and educational experiences of students with FASD: (a) "On, Yet Under, the Radar", (b) "I Don't Do Anything Differently With Oscar", and (c) "If I Had Known Then What I Know Now."

##### ON, YET UNDER, THE RADAR

*Focus on the Brain.* The diagnostic team members described how their teams were formed, the team's role, and the diagnostic team process. All the diagnostic teams mentioned the high number of children referred for diagnostic testing in the state. One psychologist from a rural team reported:

There are many undiagnosed children. We have completed over 192 referrals during year 2 of the project—we receive about 200 referrals a year. They are coming out of the woodwork; we cannot keep up, we continually have waiting lists for the diagnostics.

Gail, another FAS coordinator, explained, "The work of the diagnostic team was primarily focused on obtaining a diagnosis, so families would have an explanation." FAS coordinator Maggie described the diagnostic process:

We take referrals, schedule the team members and the family. The psychologist typically sees the child first and completes his

**TABLE 2**  
*Coding Categories*

<i>Research Question</i>	<i>Major Category/Code</i>	<i>Subcategory</i>	<i>Theme</i>
Understand how the process of diagnosis and education and community support for students and families operated	Diagnosis	• Birth history	Disconnect between perceptions of participants
	Education	• Multiple placements	
	Family & Community	• Foster or adopted care	
Understand the perspectives of the families who received these services	Behavior	• Differences in perspectives	"On, Yet Under, the Radar"
		• Problem behavior	"If I Had Known Then What I Know Now . . ."
Gain an understanding of participants' perspectives on effective practices	Effective Practices	• Things they've tried	
		• Limited support	"I Don't Do Anything Differently With Oscar"
		• Lifelong issues	
		Education teams:	"On, Yet Under, the Radar"
		• Consistency	
		• Repetition	
		• Use of schedules	
		• Providing boundaries	
		• Just good teaching	
		Diagnostic teams:	
		• Importance of the diagnosis	
		• Impact of alcohol on the brain	

testing; the speech pathologist does the communication and language assessments; the physician evaluates the child's physical condition, facial features, and determines the prenatal exposure to alcohol. We follow the University of Washington FAS diagnostic evaluation system. This results in a four-digit code and the determination as to whether or not the child has FAS.

During the interview process, diagnostic team members regularly shared their concern regarding the "impact of maternal consumption of alcohol on the brain." In fact, every diagnostic team interviewed focused on the "effects [of the teratogen] of alcohol on the brain." One physician stressed the importance of "getting the parent to understand that there is brain damage due to alcohol." Another team member stated, "There is organic and irreversible brain damage due to the alcohol consumption of the biological mother during pregnancy." Anne, a FAS coordinator, de-

scribed the behavior of the child with FAS as "what you are seeing is not noncompliance, but pathology."

Diagnostic team members and school-based educators held divergent views on the significance of the "impact of alcohol on the brain." One school administrator described his perspective on diagnosis:

The fact that you know something about this person, that they have FASD or that their mother had abused a drug or used alcohol and that this affects them is going to make a difference. And I reject that premise. I don't think it is going to make a difference; the fact that you know that is not going to change one thing in the child's life unless you get it down to the level again of what happens to the child on a day-to-day basis at home, in the community, in the classroom. How does that child learn? How do we have to teach? How do we have to, you know, adapt what we're doing, change what we're

doing to accommodate his learning needs? And that is different for a wide range of people with that diagnosis. I mean, what you do for one is not necessarily going to work for another.

*Focus on Function.* In addition to their views on the importance of the impact of prenatal alcohol exposure on the developing brain, diagnostic and school-based educators differed on the importance they placed on the diagnosis. They also differed in their approaches to teacher training and classroom practices.

One educational administrator noted, "Sending teachers off to a 2-day conference on FASD or even a week's conference is an awareness-building thing only." He explained, "Back in the classroom the following Monday, the teacher faced with the same 28 students, 2 with FASD, and the special education teacher is faced with a large workload."

None of the educators interviewed was part of a FAS diagnostic team, and few received the diagnostic report. As Annie, a FAS coordinator explained, "You see, the diagnosis is for the family and it is the family's option to share it with the school, if they want to." Jen, Ellie's teacher, was the only educator in this study to have received the diagnostic report. She shared her frustration: "The recommendations were pretty generic. There were no specific recommendations that I could use in this classroom." She wondered if that was because "no one observed Ellie in the classroom."

Despite their differences, it was clear from all the interviews that both groups recognized and were concerned by the high incidence of FASD. One principal who had worked in a remote school for more than 10 years told us, "It is as bad as it could get. Over 50% of the students, I would say, have some form of FASD."

*On the Radar.* The diagnostic team members made noticeable references to the ways in which FASD "had come to the public's attention." AOFAS had sponsored several activities aimed at "increasing the public's awareness of the issue of FAS." One administrator described the media campaign that occurred:

We have placed public service messages on the television. These messages are aimed at

increasing public awareness of the damage caused by maternal consumption of alcohol.

In one such message a woman speaks of her use of alcohol and how she was not aware of the damage that it could cause her unborn baby, but that with the advice and support of her mother she did not drink during pregnancy and today she has a healthy baby. The television messages used actors who were both Alaska Native and Caucasian.

As one FAS coordinator shared: "We hope to increase the public's awareness that this is an equal-opportunity disability. That women of all ages and ethnicities may be drinking during pregnancy."

Beyond television ad campaigns, activities in the area of surveillance and prevalence place FASD on the "radar screen." During the period in which the current study was undertaken, CDC published findings in the *Morbidity and Mortality Weekly Review* (CDC, May 24, 2002). MMWR reported the high incidence of FAS in Alaska (i.e., 1.5 live infant births per 1,000) between 1995 and 1997. Even more shocking was the prevalence rate (e.g., of FAS) of 5.6 per 1,000 live births among Alaska Native live births. One administrator noted that "These numbers may reflect the good job that the Alaska Native people are doing in identifying this disability." She went on to explain that "the numbers might be underreported in other ethnicities."

Alaska diagnostic teams reported data for the 5 participating sites indicating that Alaska Native children between the ages of 1 and 21 who have a diagnosis of FAS account for a greater than average number of the overall diagnoses completed (State of Alaska, Office of FAS Data Reporting Form, 2003). These data raise alarming questions about the possible overrepresentation of Alaska Native children. Poverty, or other conditions under which Alaska Native children may be living, may also be a factor in interpreting this data.

Participants voiced awareness of the efforts the State was undertaking to address the issue of FASD in Alaska. In fact, most participants were aware, as one administrator shared, that "the state had been given \$29 million to combat FAS." Participants recognized that with that level of funding there were "politics involved." Despite efforts

in the area of prevention and diagnosis, most participants, including one FAS coordinator, shared that "it is important that we provide services to children with FAS and their families."

*Under the Radar.* The efforts described above resulted in FASD being "on the radar screen" in Alaska. Our interviews with participants and our observations of the students themselves, however, revealed that the students themselves and their families lived daily "under the radar." Through our observations of the lives of the children and their foster or adopted families, we became aware of the invisible nature of the disability. Because, as one teacher put it, "these kids are not the worst in the class"; students with FASD may be overlooked. One special education director stressed that "FAS or FASD is not a category under the Individuals with Disabilities Education Act." Gail, a FAS coordinator, noted, "FAS is a medical diagnosis. FASD is not a diagnosis and children are not easily found eligible for special education services" (Institute of Medicine, 1996). Throughout the 3 years of the study we heard about the students' challenging behaviors (e.g., academic delays, stealing, running away, using alcohol and marijuana), yet few schools or communities had programs for children with FASD and their families. Alan's, Oscar's, and Paul's parents told us there are lots of opportunities to "get into trouble [with the law]."

In the majority of the families we interviewed, the child with FASD was in the care of foster or adopted parents (Paul, Alan, Oscar, Adam). In fact, several of the children had been in multiple foster placements or care facilities throughout their lives. Adam has lived with his biological mother, with an aunt, and is now living with his adopted mother. Oscar had lived with his mother until she died, then with an uncle, and with a grandfather, before he went to live with Richard (his adopted father). Oscar also has spent time in prison and in residential treatment facilities. Alan, adopted at birth, is now in a residential treatment facility out of state. Paul, who graduated from high school 3 years ago, has lived with his biological mother, with foster parents, and with a village elder.

As we listened to the families and observed the children across 3 years of their lives, we began to understand that these children were at risk for

"falling through the cracks." The school district where Alan attended high school did not know that his adopted parents had sent him to an out-of-state facility. In our last interview at Alan's school the PE teacher shared: "If Alan is pulled out of school I am afraid we will lose him." When we asked this teacher what he meant, he replied, "I'm afraid that he will never come back to our school or community." Alan remains in a facility 4,000 miles from his home.

#### *"I DON'T DO ANYTHING DIFFERENTLY WITH OSCAR"*

Special and general educators described their experiences with working with students with FASD. Teachers participating in this study seemed to view themselves in two very distinct groups—experienced and inexperienced teachers. Teachers who described themselves as experienced had been teaching for more than 3 years and had experience working with students with FASD. This theme captures the experiences of both groups of teachers.

*Teachers' Practices.* The quote "I don't do anything differently with Oscar" from one experienced junior high school English teacher seemed to capture her teaching perspective. During one interview, she stated, "I don't feel like I have to deviate from my normal [routine] to teach Oscar." She described her approach to teaching Oscar:

I think he's equal to all of my other students. I don't do things differently with Oscar. The only difference I might show him is spending a little more time one on one. Oscar, and a group of other students, seems to benefit from more one on one. Then there's a group of students who do well whether I'm sitting next to them or not.

As the experienced teachers described how they provided instruction for students with FASD, we noticed that a common element in their teaching was the degree to which they made slight modifications or emphasized certain strategies such as repetition, consistency, or practice. Alice (Alan's language arts teacher) described her approach:

This is my theory: they have to practice those skills. They have to make them



stronger and stronger and stronger. So more lessons isn't really the most important thing. More practice of the skills, using the skills they already have, is what's important. And that's what I'm banking on to improve reading abilities when the kids come in here. So practice, practice, practice. Because the strategies and methods that we use are very productive for all kids. You know, we modify the curriculum. We look at if it's a behavior issue, we look at what's causing the behavior and what we can do to try to prevent it and support the student. You know, we modify the curriculum. You know, and we repeat and reteach using different methods and materials.

Teachers described how they tailored their teaching to meet the needs of all students, including students with FASD. The individualized approach to teaching was used by most of the experienced teachers we interviewed. Ellie's fourth-grade teacher said, "I like to figure out where students are at and accept that and just realize that [it's] okay for them to be there and then start moving them forward." To a large extent, the teachers' experiences with the students in this study were as much about who they were as teachers, and their level of confidence and experience, as about the particulars of the students' abilities or disabilities.

Adam's teacher had a background in Montessori. Her use of redirection and setting boundaries was one of the approaches she used that was reflective of the Montessori philosophy. She explained her approach to the strategy of redirection and setting physical boundaries for Adam.

Some [strategies] are things that I've tried to think of as different redirections so that the child doesn't have to always hear: "Ok, you need to move from the group." During circle time I also have a rug, which I call my lily pad. I give it to him. This is a round rug, and in that round rug that's his perimeter. He sits on the rug. If he needs to stand, if he needs to roll, or if he needs to do whatever then that's his zone. This way he doesn't kick anybody but he still is able to do what his body needs to do and stay with the circle.

Experienced teachers also shared their belief in maintaining consistent expectations for students with and without FASD:

I keep the same standards for [kids with FASD] as I do for other kids. I may be wrong in doing that, but I think if they're gonna be in the classroom, I can't let them do things to people that I don't let other people do. I have to keep the same standards for everybody is my feeling.

Inexperienced teachers (beginning teachers as well as teachers new to working with students with FASD) also echoed the sentiment of "I don't do anything differently." "Not doing anything differently," for these inexperienced teachers, did not mean the same thing as it did for experienced teachers. Adam's first-year teacher expressed both her frustration with teaching Adam, and her inexperience with using individualized and differentiated instructional techniques:

I get frustrated with him after a while because it's over and over. I have never worked with a child with this disability before and it's hard sometimes. One week we can do a sticker chart and he's got that for a couple of days and then two days later that wasn't working so we had to come up with something else . . . It's constantly coming up with something that works . . . you have to constantly battle.

Both experienced and inexperienced teachers spoke of the students' academic performance. Jen, Ellie's third- and fourth-grade teacher, was concerned about Ellie's academic progress. Despite the fact that Ellie received resource room support in reading, writing, and math, she was reading almost two grade levels behind. Three of the 5 students (Alan, Oscar, Ellie) did not pass the benchmark tests in reading, writing, and math at any point during the 3-year study. Adam, being a preschooler, did not take benchmark examinations; yet, he was 1 year delayed in the areas of cognition and communication. Paul graduated from high school before the high school qualifying examination became a requirement.

When teachers referred to "not doing anything differently" with their students with FASD, the net perceptions of the two groups of teachers might have been the same but the underlying reasons were vastly different. Experienced teachers seemed to represent professionals who used differentiated instructional techniques and therefore assumed or expected to modify instruction for any

student. The inexperienced teachers, in contrast, did not know how to address the varying educational needs of their students, and did not seem to have access to effective staff development.

*Teachers' Training.* Our interviews with educators elicited many comments about AOFAS inservice training. While the teachers appreciated the essential benefit of training, they expressed frustration at the applicability of the content to their individual situations, as Jen, Oscar's first-year science teacher shared:

When these people come in [trainers], they do have ideas. And they say, this is the best atmosphere for the child, or this is the way you need to teach them, and they do give you ideas. But what they don't do is they don't come into your classroom to see the load that you're already carrying. You know, you have 21 or 25 kids and you're constantly having to change the subject area, move on to this or move on to that. And they tell you, this child needs this and they need this. And this child needs to be approached this way. They don't understand why you can't do that. But you almost have to be a one-to-one teacher in order to do what they're asking you to do. And that is extremely frustrating. So you get these handouts and you get these great ideas. And you go back in your classroom and there's really very little you can change.

Other educators described their preparation for working with students with FASD and the importance of training and support. One rural teacher working out of his content area told us, "It's real difficult, I was not prepared to teach reading or work with students with FAS, to be honest." Another participant, a principal, echoed this idea:

Once the diagnostic teams have been formulated then the next focus or even a prefocus has to be intervention in the school system. So somehow I think the State needs to address well-trained personnel who will go into the villages and model for teachers. Sometimes it takes an outside source to bring in a credible model that some teachers will adopt. We have our own specialist, but sometimes being local we don't always have the [pause] I don't know, I don't want to use the word power, but you know what I mean?

As the teachers shared their approach to working with students with FASD we noted that a common element across the interviews was that they "liked" the student. For example, George said: "He's [Oscar] a likeable kid. He's personable, has a unique personality. Um, and yeah, I do, I do like him a lot." Pam shared with us, "What I see is that Adam is first a little person. So yes, this child [Adam] has, uh, difficulties but I focus on his needs. And he has a right to learn too. He has the right to be happy too. I like him; he keeps me going."

*"If I Had Known Then What I Know Now . . ."*

Two of the parents interviewed (Alan's and Oscar's) described the impact of their child's disability on the family by saying, "If I had known then what I know now . . .," leaving the sentence unfinished. Even the parents who did not use that phrase described the early history of their relationship with their children, the things they had tried to respond to the challenges encountered, and the lack of or limited support from agencies and professionals. This theme dominated the stories they shared over the 3 years. It is a complex theme that highlights the reflections of families on the relentless challenges of problem behavior and lack of supports.

*Early History of Problem Behavior.* The families shared their early hopes and expectations at the time of the initial foster placement or adoption. Alan's adopted parents stated: "We adopted Alan and his brother when they were very young. We hoped that we could give them a life that they might not have had otherwise. Having two boys added to our family [they had three girls of their own]." Richard adopted Oscar after his girlfriend (Oscar's mother) died. Richard shared that he and Oscar "go to fish camp, hunt caribou and moose, and dog mush. Oscar is my right-hand man."

The families also shared many stories about the children's problem behavior, which ranged from daily annoyances (e.g., not doing chores, lying, not doing homework) to serious crises (stealing, setting fires to buildings, running away, using drugs or alcohol). Paul's foster father, who takes medicine for his emphysema, told us how "Paul stole codeine from my medicine cabinet

and \$50 from my wife's [foster mother's] purse." Oscar's father struggled with his son's escalating behaviors from what he described as "petty crime" (stealing candy from the local store) to episodes such as "siphoning gasoline from a boat to burn a shed down," "stealing the four-wheeler and running away from home for 3 days," to "being in prison for using alcohol and marijuana."

*Coping Strategies.* Parents dealt with the challenging behavior in various ways. Adam's adopted mother took off many days from work because she received multiple phone calls from child-care workers who were ill-prepared to work with her son. Cancelling an interview, she told us how she was called by the child-care program and told to come get her son. "You see," she explained, "Adam urinated on one of the other boys." "Well," she said, "the boy actually urinated on Adam first." She added, "Adam said, 'Mom, he peed on me first!'" Other parents struggled to cope with a child's challenging behavior. When Alan accessed a porn site on the computer, his parents "took away his privileges, including use of the computer, after school activities, and social events."

Because of the serious nature of many of the children's behaviors (e.g., stealing, running away, using alcohol and marijuana) and the lack of local supports, many of the parents felt that their only options were residential treatment facilities. Alan's parents "sent him to an out-of-state lock-down facility" because "we just cannot take it anymore. We've received no help and Alan is disrupting our home life. We are not a family anymore." In fact, Alan was sent to a treatment center at the end of the first year of the study and was not a part of the study after the first year. Oscar's father, Richard, shared his mounting frustration in one interview. He said, "I'm a single father. I have three other children." Richard had organized weekly counseling and behavioral health therapy for his son; yet, after 6 months when his behaviors continued to escalate, Richard enrolled Oscar in a treatment facility in a larger city in Alaska because "I just can't trust him anymore."

One of the special education directors interviewed echoed the parents' concerns and frustrations, the lifelong issues of having a child with FAS, and the lack of support services:

The parents are having a lot of safety concerns, whether it is in [name of village] or another area, there are supervision issues. Parents will go to bed and the child will get out of bed and leave the house. They might be stealing, drinking, or doing drugs. So it's very stressful for parents and sometimes they don't know who to reach out to or how to get help. And I've had some parents who are so concerned and frustrated that they tell me, "If I had known this we never would have adopted this child. Or some even saying in front of the child, 'I wish we'd never adopted you,' or 'we can't handle you.'"

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*Limited or No Support.* Many of the parents felt that they did not receive the help they needed from the social service agencies. The parents seemed to feel that once they made the decision to foster or adopt, they were "on their own without support." Richard shared that since he worked full-time and had three other children he needed help. His girlfriend moved out because things "got to be too hard." Alan's parents expressed their frustration over the lack of support: "We are on our own. No one understands our situation, in fact, we feel like they blame us for Alan's behavior. We call [the social service agency] and they say that there are no services for kids with FAS. It seems like once you adopt the child you are on your own." Paul's foster family shared that they were "probably the only folks [in the village] who would take on a child like Paul and his sister [who also experiences FAS]."

Despite the fact that the families were frustrated by a lack of services and supports, some families were able to access limited support. Lillian (Adam's adopted mother) shared that she "receives respite care" and that her neighbors were "a godsend." Richard told us that the social service

agency eventually provided Oscar with counseling.

The support some families received, however, did not appear to be consistent or sufficient. Over the 3 years of the study, we observed the numerous attempts parents made to secure help for their children, the many meetings or phone calls, and the emotional toll it had on them. Whether it was the child's problem behavior, ineffective coping strategies, or the limited support received, families revealed the frustration and overwhelming sadness related to parenting a child with FASD. According to these families, the long-term impact of the disability was never conveyed by professionals nor fully realized by parents. In one of our last interviews with Richard, he shared his anguish and frustration.

Interviewer: "I want to read to you something that you said in one of our interviews. You said: 'If I had known then what I know now . . .' You did not finish that sentence then. Can you finish it now?"

Richard: "Yes, I did say that. Well, I said: If I had known then what I know now I would not have adopted Oscar. I love him. I just cannot do this alone anymore. If I had known it [Oscar's challenging behaviors and no support] would be like this when he was little I might not have taken him on."

#### *REACTIONS FROM THE PARTICIPANTS*

We provided each person interviewed with a copy of a draft of the major themes. The participants agreed that the findings were reflective of their experiences. Several provided us with updates on events, which we then incorporated into the findings; and we continue to maintain regular contact with the families. Parents shared that they hoped that their stories would help other people. For example, Oscar's father said, "The findings are right on and I hope this study helps other families obtain the services that I did not receive." Lillian, Adam's mother, wrote "You captured my situation with Adam well." One principal wrote, "These kids really are under our radar screen."

## **DISCUSSION AND IMPLICATIONS**

### *RECURRING THEMES*

As reported in the preceding section, data analysis revealed three themes that represented the participants' experiences with supporting the needs of students with FASD.

The first theme focuses on the extent to which students with FASD and their families exist at one level "on the radar," and on another level "under the radar." Participants said that (a) an understanding of the impact of prenatal exposure to alcohol on the brain was essential; (b) a student with FASD should be understood within the context of developmental history and functioning abilities (Bronfenbrenner, 1979; Turnbull & Turnbull, 2001); (c) students with FASD were "on the radar" as a result of prevention campaigns, diagnostic activities, and funded projects; and (d) students with FASD were "under the radar screen" as a result of multiple home placements and inconsistent special education services.

The second theme concerns educator experiences. The data revealed that experienced teachers used a variety of professional practices to differentiate instruction for students with FASD (Ford, Davern & Schnorr, 2001; Salend, 2005). Inexperienced teachers did not use differentiated instruction practices, which underscores the importance of professional development and teacher mentoring (Conderman & Stephens, 2000; Daresh, 2003).

Finally, the third theme addresses family experiences. Families said that (a) the challenging behaviors of their child were often overwhelming; (b) their frustrations were often linked to the absence of community and school-based services; and (c) the pervasive, persistent, and challenging nature of their children's behaviors and functioning, coupled with the lack of supports, affected family relationships, physical circumstances, social networks, and daily activities (Fox, Vaughn, Wyatt, & Dunlap, 2002).

These recurring themes emphasize the critical and immediate need for coordinated services for students with FASD, and supports for their families. We hope these findings lead practitioners to envisioning and shaping effective services and supports for students and their families.

### *LIMITATIONS OF STUDY*

The findings are limited in four ways. First, they represent the perspectives of 71 participants who lived in five areas across Alaska. Including participants from other areas in Alaska or across the United States may provide richer data and result in additional or different themes. Second, the interviews are based on 3 years of data collected predominantly by the lead author. The data represent those perspectives that the children, their parents, and other participants felt free to share. Although the lead author established considerable rapport and trust with the children and their families, participants may have been unwilling to share all their most intimate concerns and challenges. Third, the children who were the focus of this study were between the ages of 3 and 19 (at the start of the project) and included 4 boys and 1 girl. Including more female students may have provided different themes. Finally, 5 students were the focus of this qualitative study. As such, the study represents findings that are applicable only to these 5 students' lives.

### *IMPLICATIONS FOR FUTURE RESEARCH*

Potential research questions for future investigations include:

- What are the perspectives of students with FASD?
- Why are children from minority cultures overrepresented in the population diagnosed with FAS? Is an overrepresentation of children from low socioeconomic groups being diagnosed with FAS?
- What factors contribute to the lack of provision of services and supports for students with FASD? What specific supports do families identify as helpful? Why are families not receiving these services?
- Are interventions such as positive behavioral supports beneficial for individuals with FASD? What specific types of interventions and supports are most effective with students with FASD?
- What types of social, cultural, economic, political, and systemic factors affect services for students with FASD and their families?

### *IMPLICATIONS FOR SERVICES TO STUDENTS WITH FASD*

We suggest above that coordinating services between diagnosis and intervention might benefit students with FASD and their families. Our findings suggest that in addressing the needs of students with FASD, diagnosis should be followed by providing intervention and services for the student, as well as by identifying the family's support needs. Linking diagnosis, intervention, and services (Bricker, 1998); providing differentiated instruction (Salend, 2005); and identifying formal and informal supports for families (Dunst & Paget, 1991) all contribute to improving services for students with disabilities and their families.

Professionals should also recognize the high incidence and prevalence of FASD. The Substance Abuse and Mental Health Services and Administration (SAMHSA) reports the prevalence of FASD at 10 in 1,000 (SAMHSA, 2005). According to SAMHSA, the prevalence of FASD is higher than that of autism spectrum disorder. Beyond recognizing the increase in the incidence of FASD, professionals should investigate the potential overrepresentation in the population diagnosed with FAS of Alaska Native children, or children of other ethnic or low socioeconomic groups. In the current study, 73% of referrals to AOFAS diagnostic teams between 1999 and 2003 were for Alaska Native or American Indian children. When all ethnicities were included, 80% of the referrals to the diagnostic teams were for non-Caucasian children, including African American, Alaska Native, American Indian, Asian, Native Hawaiian, or Hispanic/Latino children (Ryan & Dybdahl, 2004).

The disproportionate identification of minority students with specific learning disabilities is well established (Artiles, Trent, & Palmer, 2004; Dunn, 1968; Salend, 2005). Since issues of disproportionality are multifaceted and shaped by the cultural experiences of professionals (Knotek, 2003), educators need to "examine whether their policies, practices, attitudes, and behaviors result in disparate treatment and disparate impact on students from culturally and linguistically diverse background" (Salend, p. 22).

Parents and educators voiced their frustrations with the fact that FAS and FASD are not

IDEA eligibility categories. Although students with FAS or FASD may be diagnosed with other disabilities such as ADHD, autism, learning disabilities, or emotional disturbance (Streissguth, 1997), many students with FASD fall between the cracks and may not be referred for special education upon diagnosis. Families who care for children with FASD might learn from the efforts of parent organizations for children with autism spectrum disorders (National Research Council, 2001). Parent organizations have been effective in advocating for an awareness of the needs of students with disabilities and the subsequent provision of necessary supports and services (Katsiyannis, Yell, & Bradley, 2001; Turnbull & Turnbull, 2001).

The results of this study indicate that children with FASD often have not received the critical supports and services needed to avoid problematic outcomes, including disruptive home and school experiences, suspensions or expulsions from school, and prison (Streissguth et al., 2004). Our findings may further suggest similarities in the needs of groups of students with challenging behaviors (e.g., autism spectrum disorders, emotional disturbance). Research in the area of challenging behaviors highlights the need for comprehensive, positive behavioral supports (Lucyshyn, Dunlap, & Albin, 2002), to minimize the impact of problem behavior on the family (Fox et al., 2002; Turnbull & Ruef, 1996). Fox and colleagues, in summarizing the work of Keogh, Garnier, Bernheimer, and Gallimore (2000), noted that "family accommodations need to be more extensive as the problem behavior often becomes increasingly severe as the child grows older" (p. 449).

The current study reveals the increasing severity of challenging behaviors in children with FAS (Alan, Oscar, Paul). It is critical for educators and policymakers to understand the individual needs of students with FASD and the potential applicability of research on challenging behaviors, positive behavioral supports, and coordinated systems of support for children with FASD. The possibility that supports found effective for children with autism and other challenging behaviors may be equally valuable for children with FASD warrants further investigation.

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The perspectives of the families who adopted or fostered children with FASD described in this article highlight the critical needs of children with FASD, the needs of their families, and the lack of a coordinated policy on service provision. The longer that family needs are left unmet, the more the child is at risk for losing placement with the family. The major contribution of the current study is to highlight the needs of students with FASD and their families and the impact of lack of services on the lives of the children and their families. The opportunities which lie ahead are to (a) develop an increased understanding of the education and community needs of individuals with FASD, (b) create programs and services to meet the children's and their families' needs, (c) build coordinated services across agencies to link a medical diagnosis with an educational and community-based assessment and intervention, and (d) include FASD in special education research and program implementation agendas.

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