

Eddie With FAS: Getting What He Needs in a Remote Alaskan Community

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Introduction

When Eddie was delivered, doctors immediately suspected that he had been prenatally exposed to alcohol. They did not, however, give him a diagnosis of Fetal Alcohol Syndrome (FAS). During a routine home visit three weeks later, the local Public Health Nurse determined that all the primary adults in the home were intoxicated. The Division of Youth and Family Services took Eddie into custody and a foster family was found. He was immediately hospitalized because at three weeks, Eddie had not yet opened his eyes. Local doctors and his new foster parents were concerned that Eddie might be blind.

Alaska has one of the highest documented incidences of Fetal Alcohol Syndrome (FAS) in the United States. Over 20,000 Alaskan women of childbearing age have acknowledged that they are heavy drinkers (DHSS, 1997). Incidence rates are reported as 1.4 per 1000 live births, about four times the national average (State of Alaska, 2001, p. 1). Yet what does it mean to Eddie to be one small part of these statistics? Can he receive in his small, remote northern community the diagnosis and services he needs? If so, how does it happen?

In this article we will (1) review the diagnostic descriptions of FAS, (2) outline the needs of a person with FAS across a life span, (3) discuss how these needs are met in rural Alaska in the hope that this experience will benefit other remote communities, and (4) describe what Alaska and other remote communities still need to help people like Eddie.

Defining FAS

Eddie's new family provided foster care to several children who had been prenatally exposed to alcohol—one of them was Christopher. Eddie's foster mother, Marilyn, had learned from "wisdom of practice" with her other children that Eddie would need specialized care and extensive support services to help him grow into a healthy, self-confident individual. As a

baby Eddie would lie in his crib with his arms drawn underneath him. He was rigid, highly sensitive to noise and disliked soft touch.

There is no biochemical test to determine if a child has FAS. Eddie displayed many of the characteristics of this disorder at birth and it was known that his mother had consistently abused alcohol during her pregnancy. This can cause problems, because "Alcohol is a neurobehavioral teratogen, an agent that can cause defects in the structure and function of the developing central nervous system in humans" (Olson, Morse, and Huffine, 1998, p. 262). FAS is characterized by (1) pre- and post-natal growth deficiencies that place a child below the tenth percentile for height or weight or both, (2) a distinct pattern of facial features, and (3) evidence of central nervous system (CNS) damage.

Prenatal alcohol exposure does not always result in a child having FAS. Some children have partial manifestations of the disorder, usually CNS damage. These individuals are described as having Fetal Alcohol Effects (FAE) or an alcohol-related neurodevelopmental disorder (ARND). FAE is not a less severe form of FAS. Quite the contrary, children with FAE often experience worse problems in school and as adults because many people do not perceive them as having brain damage since they lack outward signs of a syndrome (Streissguth, 1997a).

The central nervous system (CNS) dysfunction associated with prenatal alcohol exposure can cause learning deficiencies (i.e., lower IQ scores), auditory, verbal, and spatial memory difficulties, problems in visual-spatial skills, hyperactivity, attention deficit problems, motor delays, problems with organization, and speed of information processing (Olson, Morse & Huffine, 1998; Streissguth, 1997a). While children with FAE often have a variety of these CNS difficulties, their problems are less likely to be recognized, and they tend to receive less help and support.

FAS/FAE is considered an equal opportunity disorder. Wherever women drink heavily, children with FAS are born. The likelihood of a woman who persists in a chronic drinking pattern of producing more than one child with FAS is very high (Astley, Bailey, Talbot, & Clarren, 2000).

People with FAS/FAE are in need of a variety of services to help them live safe and healthy lives. First, they need a diagnosis in order to access needed services and understanding. Second, they need consistent supportive family care. Many children with FAS may require foster care because their own family is not stable enough to care for them. Third, they need early intervention and adapted school services. Fourth, they frequently need medical and therapy services. And finally, many require supportive living assistance throughout their lives to help them understand the daily demands of community life.

Getting a Diagnosis

Eddie did not officially receive a diagnosis of FAS until he was five and was seen by a specialist. His foster brother Christopher was diagnosed with FAE at age nine. Christopher had trouble understanding what people said and was easily frustrated when he did not respond correctly to things people asked him to do. Fun, artsy, fine motor tasks aggravated him. Teachers and doctors without knowledge of FAS/FAE found most of his behaviors frustrating and puzzling.

The diagnostic conditions for FAS are clear and descriptions of the disorder and its consequences are fairly well documented. Yet, FAS is still largely misunderstood by community members and professionals. Often FAS/FAE as a disability goes undiagnosed because of 1) the lack of accessible medical practitioners who know about FAS, 2) the tendency by medical and other health care professionals to avoid issues where alcohol use or abuse must be confronted, and 3) the variance in the facial characteristics and cognitive behaviors as people age.

Ann Streissguth, a leading researcher in the field of FAS, describes FAS as a "hidden" disability because people with FAS often seem normal and fail to meet qualifying criteria for community support programs designed to help people with disabilities live productive lives. She clarifies why FAS confounds people:

Individuals with FAS/FAE are born with organic brain dysfunction, which constitutes their primary disability. Although the manifestations may change as the child matures, the brain damage remains a part of their endowment across a life span. Because of the complexities and unevenness of the brain damage, people with FAS/FAE may be good at some things and disabled at others. They may have normal overall performance on an IQ test but nevertheless have significant disabilities with abstract thinking, learning and generalizing from their past experiences.

Streissguth goes on to describe what FAS looks like in everyday life:

They may read well but have difficulty comprehending the subtle social cues of interpersonal relationships. They may talk a lot but lack insight into their own behavior. They feel distress but may be unable to articulate their needs to others. They may have difficulty modulating incoming stimuli and be in danger of being overwhelmed by stimulation and of behaving in an impulsive and maladaptive fashion. They may lack the ability to evaluate their own performance, set realistic goals and organize their behavior to work towards a goal. These characteristics, so well known to everyone who lives and works with people who have FAS/FAE, are signs of brain dysfunction. (1997a, p. 146)

Evidence suggests that if FAS is left undiagnosed into adolescence the probability of poor life outcomes increases (Streissguth, Barr, Kogan, & Bookstein, 1996).

Eddie and Christopher were diagnosed at the specialty clinic held at the local hospital in their community. The local FASTask Force, a team of concerned community volunteers, raised the money to pay for Dr. Sterling Clarren, a noted FAS researcher and dysmorphologist at the University of Washington, to come to the community. The local hospital provided space for the clinic and Dr. Clarren helped train local pediatricians in making a diagnosis. These types of community-sponsored clinics occurred sporadically because fundraising was time-consuming, arranging village travel was difficult, and scheduling time with a single specialist was almost impossible. While Eddie and Christopher did eventually get a diagnosis, many other children in remote northern communities do not. That children have not been diagnosed has been a consistent complaint in Alaska. Many families have had to travel to larger city centers to get help for their children.

Early Intervention

Eddie and his family enrolled in a community-based Infant Learning Program (ILP). Therapists and educators worked with his family on activities that would help Eddie learn to self-calm and begin to integrate the sensory experiences that easily overwhelmed him. Eddie also required physical therapy to help reduce the rigidity that was inhibiting his use of his arms. A speech and language pathologist saw him every six months to offer support to his mother by discussing feeding and calming activities.

The key to helping individuals with FAS/FAE is often said to be early and consistent intervention (Hinde, 1993):

Given the plasticity of the young brain and the potential for early intervention to effect actual neurological change, early intervention might minimize alcohol's adverse impact on the CNS.... This could possibly improve the quality of the essential caregiver-child attachment relationship, laying a more secure foundation for later development. (Olson, Morse, & Huffine, 1998, p. 275)

But we must keep in mind: to be eligible for early intervention it helps if a child has a diagnosis.

The state of Alaska supports Infant Learning Programs (ILP), early intervention programs that provide voluntary, family-centered services to

assist families in coping with the demands of a child with special needs. The services are offered free of charge to the families. Medicaid or private insurance covers the cost of physical therapy, occupational therapy, speech and language pathology, audiology, and other special clinic services. The state of Alaska provides the funding to cover some of the other services that families need.

ILP services are made available in every community in Alaska by traveling teachers and therapists. Most rural ILP programs have staff that travel long distances to work with families who request help. In July 2000, in the program that Eddie was a part of as an infant, 10 percent of the children on the case load had been prenatally exposed to alcohol.

Eddie was in the ILP program for three years. His mother feels that it was the best-designed and most supportive services she and Eddie have received to date. She appreciated that the services were family-centered and home based. Eddie was fortunate as his foster parents and siblings were reactive, knowledgeable participants in his early education program, often teaching the teachers a lot about him. While Eddie was privileged in having a foster mother who knew how to address his rigidity and resistance to soft touch, many parents find children with FAS/FAE difficult to nurture.

Middle School Woes

School was rough for Eddie. He was extremely hyperactive and his attention span for activities he didn't enjoy, like math, was about one minute. His verbal expression skills were excellent. He had fine motor troubles that made writing a difficult task for him. Teachers reacted differently to his behaviors and needs. His activity level and gullibility amazed other children and this often led to teasing. As other children teased him and teachers had unpredictable responses, stress at school mounted. His behavior at school would breakdown to the point where he was described as "Mr. Hyde" (demon) at school and "Dr. Jekyll" (angel) at home.

Eddie's behavior problems are typical of what is observed in children with FAS/FAE in school. Children with FAS have difficulties attending to tasks, sitting still, dealing with changes in schedules, taking notes, and staying organized. They frequently have specific speech and language problems that affect their day-to-day functioning and social success. They often appear to be fluent talkers but having lots of words does not mean that they understand how to use those words to influence social situations. "Deficits

in social communication jeopardize academic success and appear to play a major role in maladaptive and dysfunctional behaviors present in older children and adolescents with FAS" (Coggins, Friet, & Morgan, 1997, p. 221).

Teachers typically interpret these problems to mean that a child needs special education. In large school settings with many special education teachers, children can be taken out of the classroom to work on areas of breakdown. In smaller, more remote sites, the special education teacher is often responsible for the needs of all children experiencing difficulties in the school and children with FAS don't get the help they need. Even for a special education teacher, the demands of a child with FAS/FAE can be unsettling. Parent and FAS advocate Jan Lutke points out that "At the heart of all compliance issues is a competence issue. We have to move from seeing behavior as non-compliance to seeing it as non-competence" (1997, p. 184). When teachers focus specifically on the bad behaviors of a child, they can forget to examine if that child actually has the necessary skills to complete the tasks they are asking that child to perform.

Atagenine, Eddie's problems in school became so severe that his foster mother decided to homeschool him. Clashes with well-intentioned teachers who did not understand his disability and worries about his safety on the playground, close to the busy road, made the home placement more acceptable to his family. Currently, at age thirteen, Eddie attends public school in theory only. His mother, who receives limited technical support from the school district itinerant specialist, instructs him.

Many children do not have the supportive family that Eddie has. Nor do they have a parent who is able or willing to educate them at home. Many children with FAS/FAE who act out in class get suspended from school or drop out, leaving them in the community with compromised skills and poor coping behaviors (Streissguth, 1997a). This is an emerging problem for individuals with FAS/FAE in Alaskan schools and communities. Many adolescents and adults who were prenatally exposed to alcohol and not diagnosed are appearing in the courts, forcing the legal system to make accommodations in order to deal judiciously with them in the criminal process (Dagher-Margosian, 1997). This problem is just beginning to be examined by the state.

Adolescence and Adulthood

As Eddie reaches adolescence his mother worries if she will be able to head off the frustrations she experienced with Christopher when he reached his teens. Christopher wanted more than anything to be finished with school,

been employed fulltime, and have his driver's license. Yet Christopher had only a vague idea of how to handle money and still needed assistance to schedule his day. He had few friends and was easily frustrated by people not familiar with his abilities. He was consistently distressed when he could not make clear his needs and thoughts. After a frustrating experience at his part-time job, Christopher took his life at sixteen years of age by hanging himself.

Many parents succeed in providing the structures and routines, visual and experiential approaches to learning, and fierce love and security that enable young children with FAS/FAE to thrive. But their sense of success is tempered by the anxiety that adolescence lies ahead, blocking the road like a gigantic boulder. They know from other parents that, at adolescence, things often fall apart (Kleinfeld, 2000, p. 327).

Mental Health Needs

Adolescence is difficult for young people with FAS/FAE because this stage of life brings expectations for independence and achievement beyond what most can achieve. High school itself presents a difficult set of challenges for children with FAS/FAE, such as dealing with room changes and the subtlety of teenage social demands. Many individuals with FAS/FAE become angry and depressed, sometimes suicidal, and need mental health support. However, counselors often feel that they don't have the skills to deal with individuals with FAS/FAE (Kleinfeld, 2000, p. 340). Many mistakenly believe that insight therapy and other strategies commonly used to help people do not work with adolescents with FAS/FAE, even though therapists have found ways to adapt therapies so they are effective (Baxter, 2000).

Trouble with the Law

Young people with FAS/FAE are at much higher risk for breaking the law. A study by Streissguth, Barr, Kogan, and Bookstein (1996) on the secondary conditions that develop in people with FAS/FAE as a result of not receiving appropriate support found that sixty percent ended up having trouble with the law (p. 42). Desperate for friends and wanting to fit in, many young people can be easily persuaded to do something illegal. Many are intellectually and socially immature and do not understand what committing an offense means.

Supported Employment and Living

People with FAS/FAE need to have practice apprenticeship opportunities to learn job skills. They often require specialized job coaching and ongoing

case management to help them achieve success at a job site. Independent living rarely succeeds for this vulnerable population. People with FAS/FAE need supported living environments where other people assist them in meeting the demands of a day (Streissguth, 1997, p. 203).

Eddie's family expects that he will need a supportive living environment for his entire life. These types of placements are very difficult to access in rural communities. However, the Developmental Disabilities Program under the Department of Health and Social Services and many Village Councils are working to make supported living a reality in smaller communities. Eddie will also need a job coach or a sheltered work environment. His family is attempting to foster independent recycling work skills in him in the hope that he might work at the local recycling project. The unfortunate truth, however, is that jobs for persons with disabilities are exceptionally hard to find in small villages, where few jobs exist for anyone.

Progress That Alaska Has Made

Eddie sees his favorite pediatrician about once a month. He is on medication to help him attend to tasks and to be less active. The doctor works closely with Eddie's family to monitor his success on the medications as previous medications had caused some negative side effects. His doctor recently went to Seattle and Anchorage to receive training in diagnosing and understanding the needs of children with FAS.

In 2000 Alaska received a five-year, \$29 million grant from the federal Substance Abuse and Mental Health Services Administration to battle Fetal Alcohol Syndrome. The monies will be used to create community diagnostic teams, build needed community supports, and improve prevention activities.

In Alaska nine diagnostic teams trained by the FAS Diagnostic and Prevention Network in Seattle are in place in eight communities, with six additional teams being trained in 2002. Each team is made up of volunteers with expertise in medicine, psychology, family support, treatment, and education such as doctors, teachers, and parents. Teams offer diagnostic services in a child's home community or in the nearest rural hub. The teams also operate as communication centers, fostering improved inter-agency communication and co-operation, and alerting parents to available programs and services.

Alaska continues to fund infant learning services throughout the State. Alaska sponsors the Denali Kidcare program, which is an insurance program

for mothers and babies to ensure that no child is without medical insurance.

School supports are getting better. Alaska law requires that all teachers who enter the classroom know something about FAS/FAE. Many districts sponsor training programs for teachers to help them work with children with FAS. The Department of Education and Early Development (EED), in partnership with the DHSS Office of FAS has hired a full-time FAS Education Specialist to work with schools across Alaska. The EED FAS project provides statewide assistance through training, technical assistance, mini-grants, and support to schools. Through this project, the FAS Education Specialist will travel to school districts that desire assistance in developing specific strategies for working with children affected by prenatal alcohol exposure in their care.

Conclusions

Most days Eddie is an extremely content person. He reads, watches the Discovery Channel, and organizes his Lego. He helps with chores around the house and plays with his few devoted friends. He likes fantasy play and tells elaborate stories about heroes and villains that are fun to hear.

While preventing FAS/FAE is a top priority in every community in Alaska, small northern communities must insure that people with FAS already in the community are adequately supported. Alaska has pioneered several programs that other remote northern communities might wish to consider. First, and most important, are diagnostic teams, which can be trained at centers like the University of Washington, who return to remote communities and offer help with diagnostic and other services. Second, Infant Learning Programs are crucial for both avoiding later behavior problems and teaching families how to be advocates for their children. Alaska uses itinerant teachers and therapists with considerable success to provide ILP services. Third, educating teachers on the many expressions of FAS/FAE and providing appropriate special-education services is critical to avoid their misinterpreting behaviors. While most teachers in Alaska do receive some instruction through in-service programs, the need for continued training remains. The needs of children with FAS/FAE often overwhelm teachers, especially in small schools. Itinerant special education teachers and FAS educational support programs help. Finally, young adults with FAS need improved mental health services, sheltered employment, and supported living opportunities.

Alaska is beginning to make progress, in part through local Native organizations and community task forces. While none of these services are enough, Eddie with FAS—who is one small piece of a large statistic—is

starting to get what he needs.

Dedication

This article is dedicated to Eddie and Chris who let us tell their incredible story. We love you.

About the Authors

Maureen Harwood received her Master's degree from the University of Alaska Fairbanks in 2002. The focus of her studies was people with FAS and their needs within Alaska's criminal justice system. She is a long-time advocate of Alaskans with FAS. She currently works for the State of Alaska's Developmental Disabilities Program. Eddie is one of her heroes. Judith Smilg Kleinfeld is professor of psychology at the University of Alaska Fairbanks and Director of the Northern Studies Program. She has pioneered "wisdom of practice" studies in how to parent, teach, and counsel young people with fetal alcohol syndrome. Her books include *Fantastic Antone Succeeds* and *Fantastic Antone Grows Up*.

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