

On the Spectrum: Similarities and Differences Between Students with Fetal Alcohol Spectrum Disorders and Autism Spectrum Disorders in Ireland

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This qualitative investigation was conducted with four students with Fetal Alcohol Spectrum Disorders (FASD) and two students with Autism Spectrum Disorders (ASD) in Ireland. Data were obtained from open ended interviews with the families, educators, and other professionals. The data revealed three major themes: (a) how the process of diagnosis and education for students with FASD and ASD differed; (b) dreams, hopes, and experiences of the families; and (c) experiences of the practitioners who worked with students who experienced FASD and ASD. Data were discussed in terms of the value of gaining more insights into evidence based practices, and the similarities in education and family support services which benefit students with ASD as well as FASD.

INTRODUCTION

Within the last ten years, not only have the descriptions of fetal alcohol syndrome (FAS) and autism been increasingly refined, but the concepts have been extended to that of a spectrum disorder, (Gillberg, 1995; Lord & Risi, 2000, SAMHSA, 2005). Identified by Lemoine in 1968 as fetal alcohol syndrome (FAS), fetal alcohol spectrum disorders (FASD) refers to a wide spectrum of alcohol related neurological disorders which describe the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications (NOFAS, 2004; SAMSHA, 2005). Identified by Kanner in 1943, the term autism spectrum disorders (ASDs) and pervasive developmental disorders (PDDs) are currently used synonymously to refer to a wide spectrum of neurodevelopmental disorders that have three core features: impairments in social interactions, impairments in verbal and nonverbal communication, and restricted and repetitive patterns of behavior (American

Psychiatric Association, 1994; Institute of Medicine, 1996; Wetherby & Prizant, 2000).

The epidemiology of FASD and ASD has recently become quite controversial. In 1996, researchers at the Institute for Medicine estimated that between 0.5 and 3.0 of every 1,000 infants each year are born with some degree of FAS (IOM, 1996). In 2005, however, the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMSHA) report an increase in the rate of FASD to 10 per 1,000 live births (SAMSHA, 2005) or 40,000 babies born each year with FASD in the USA.

The increased demand for autism-specific services in the United States has drawn attention to growing numbers of children with educational categorization of autism (NRC, 2001; Odom, Brown, Frey, Karasu, Smith-Canter, & Strain, 2003). The United States, Department of Health and Human Services, Centre for Disease Control and Prevention (2005) reports the rate of ASD as 3.4 to 6 per 1,000 live births or 24,000 babies each year who will "eventually be diagnosed with an ASD" in the USA.

Ireland currently does not maintain a birth registry documenting the births of children by disability category; therefore, specific statistics on children born with FASD or ASD are not readily available. However, using the SAMSHA (2005) rate of FASD (e.g., 10 per 1,000 live births) in the

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United States and applying it to the most recent full-year figure for births of 60,503 (2002 Ireland Census), the rate of FASD in Ireland would be 605 babies born each year. Fitzgerald and colleagues (2002) report the prevalence rate of ASD in Ireland as 60 per 10,000 births. This figure was based on data collected between 1992-2001 in three health board regions in Ireland. Using Fitzgerald and colleagues' prevalence rate of 60 per 10,000 and the 2002 Ireland Census figures on births, the estimated number of babies born each year in Ireland with ASD would be 363.

The above estimated prevalence and incidence rates of FASD and ASD in Ireland would tend to substantiate SAMHSA (2005) assertion that FASD "now outranks Down Syndrome and autism in prevalence." Furthermore, the prevalence and incidence rates of both FASD and ASD have increased in the last decade. The US National Research Council (2001) offers two potential explanations for the increase in the prevalence and rate of ASD in the United States: (a) more complete diagnoses; and (b) broader definition of autism spectrum disorders (Fombonne, 1999; NRC, 2001). These explanations would appear to reasonably account for the increase in the prevalence and incidence of FASD in general, as well as, the increase of ASD and the possible increase of FASD in Ireland.

Research on Evidence Based Practices

In addition to the rise in epidemiology studies of the incidence and prevalence of ASD there has been a plethora of research on best educational practices for students with ASD. In fact, research documents evidence based practices for students with ASD include: (a) discrete trail training; (b) assessing student progress; (c) shaping, chaining, and generalization training; and (d) milieu training (Scheuermann, Webber, Goodwin, & Boutot, 2003; Irish Department of Education and Science, 2001). The US National Research Council's (2001) recommendations regarding characteristics of effective intervention include (a) a minimum of 25 hours a week, 12 months a year; (b) systematically planned, and developmentally-appropriate educational activity; (c) individualized attention to meet identified student objectives; and (d) instruction in the areas of functional spontaneous communication, social interactions, play and proactive approaches to behaviour.

Much of the research in the area of FASD has focused on the issues of incidence, prevalence, prevention, and diagnosis (Astley & Clarren, 1997; Jones & Smith, 1973; NIAAA, 1987); investigations into attitudes toward alcohol consumption in pregnant women (Halmesmaki, 1988; Streissguth, 1997); perceptions of medical personnel of the impact of maternal consumption on the developing fetus (Dufour, William, Campbell, & Aitken, 1994); and the effects of alcohol on the brain of the fetus (Aronson, 1984). Despite the focus of research on the diagnosis of FASD, and the descriptions of the characteristics of the children,

there has been almost no systematic research either on the educational needs of students with FASD, or on best educational strategies (Streissguth, 1997). While increases in incidence and prevalence of both FASD and ASD have been witnessed in the last 10 years, research efforts have not occurred on evidence-based practices for individuals with FASD.

Given (a) the incidence and prevalence of both disorders; (b) the commonalities in impairments (in behavior and learning) of both disorders; (c) the increase in research identifying recommended educational practices for students with ASD; and (d) the lack of research identifying recommended educational practices for students with FASD, an investigation regarding the similarities and differences (e.g., of need) between students with FASD and ASD was undertaken. The purpose of the current study was to determine how the process of diagnosis, education and community support occurred for families of children with FASD and ASD. A second purpose was to understand the perspective of families and professionals regarding the provision of services for students with FASD and ASD in Ireland. This study uses a qualitative research approach to examine the similarities and differences between the students "on the spectrum" of either FASD or ASD.

METHODS

Participants and Settings

Participants and associated contexts in which this study was conducted were deliberately sampled to maximize diversity of population and geographic location in Ireland. The 25 individuals interviewed (connected with the 6 focus student participants) included the foster and biological parents, special and general educators, principals, superintendents, social workers, counsellors, physicians, psychologists, and psychiatrists. The six student participants were recruited from FAS Ireland and Irish Regional Health Service Boards.

There were six key participants, five boys and one girl, who ranged in age from four to nine years old. In terms of ethnicity, three of the six students were identified as Travellers and three were identified as Caucasian. All of the children with FASD lived with foster parents; one child with ASD lived with his biological parents and the other child with ASD lived with foster parents. All participants lived in the Republic of Ireland. Three of the participants lived in counties in the west of Ireland (e.g., north, northwest, and west), two lived in north central Ireland, and one lived in a large urban area. The two students with autism had received a diagnosis of autism by the age of three. Of the four students prenatally exposed to alcohol, one student was diagnosed with fetal alcohol effects (now termed as Alcohol Related Neurodevelopmental Disorders), and another student was diagnosed with FAS.

Data Collection

The first author established rapport with the six students, their families and teachers over an eight month period in the context of two site-visits per child. Data were collected in three ways: (a) individual semi-structured interviews; (b) participant observations in the students' classrooms and homes; and (c) informal data volunteered through email or telephone conversations.

An initial interview guide was developed and contained open ended prompts for questions about: (a) understanding how the process of diagnosis, education, and community support for students and families occurs; (b) understanding the perspective of the families who receive these services; and (c) gaining an understanding of the perspective of the stakeholders on the provision of services for students with FASD. The interviews lasted from 45 minutes to one hour. All interviews were audio taped for later transcriptions and coding analysis. All together, over eight months, 22 interviews with 19 participants were completed resulting in 380 pages of typed double spaced interviews.

Data Analysis

All interviews were transcribed and coded as the study progressed. Reports were generated by student participants according to major coding categories. As each interview was coded by the first author it was entered into HyperQual 3 (Padilla, 1999), a text sorting program designed to assist in qualitative data analysis. The length of the interviews entered into Hyperqual ranged from six pages to 44 pages, an average interview was 25 pages in length, and the total number pages was 380 pages.

The interviews were analyzed inductively using categorical coding (Bogdan & Biklen, 1998; Denzin & Lincoln, 2000) and contextual comparison analysis (Maxwell, 1996). The first author conducted the initial and final codings and analyses of the interviews as the study progressed. The second author discussed the confirmability (the degree to which the themes were grounded in the data) and the dependability (the degree to which the research procedures were consistent and valid) (Lincoln & Guba, 2000; Kasahara & Turnbull, 2005).

FINDINGS

Three 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 & Biklen, 1998; Denzin & Lincoln, 2000), the responses of participants were analyzed both logically and relationally to arrive at three themes: (a) From "There is no process" to "There are specialized and individualized services;" how the process of diagnosis, education, and community

support for students with FASD and ASD operated; (b) From "No one listens" to "I've had to fight:" hopes, dreams, and experiences of parents; and (c) "Something needs to be done:" practitioners' recognition of the needs of students with FASD and the disparity between services for students with FASD and students with ASD.

"There Is No Process" For Children with FASD (From "There is No Process" to "There are Individualized and Specialized Services")

Diagnosing FAS. Of the four students with FASD, one received a diagnosis at birth of fetal alcohol effects, one received a diagnosis of fetal alcohol syndrome and two do not have a diagnosis. The foster parents of the students without a diagnosis told us that their children had been "prenatally exposed to alcohol."

We asked participants to describe their experiences of the processes of diagnosis, educational placement, and service provision. All of the parents of the children with FASD in this study were foster parents. They shared that there "was no process" for diagnosis. Their comments were echoed by the professionals we interviewed. The following three quotes, the first by a pediatrician, the second by a psychologist, and the final one from a foster parent describe the process of diagnosis for children prenatally exposed to alcohol in Ireland.

I suspect that children with fetal alcohol, assessed with alcohol syndrome often don't, first of all they may not be diagnosed, and even when they're diagnosed it's not a label that's always easy to apply if they're still in the care of the parents. I think the last thing that the parent [birth parent] would want was a diagnosis of fetal alcohol syndrome. We do not have a formal process for diagnosis of fetal alcohol syndrome in Ireland [pediatrician].

I think an awful lot of them are not diagnosed that have FAS, and there are a lot of kids out there.

I think it's not useful to just ignore the fact that it's [FAS] there if you think it's there. It's not useful to go around it, call it ADHD and leave it at that, but I think at the same time it's the individual that we need to focus on. FAS is a no go topic, it is taboo. Psychologists mostly call it generalized learning disability, because many people (psychologists) are uncomfortable diagnosing FAS. I think it is because of the stigma attached to FAS and the grief it would pose to the family [psychologist].

There's no diagnosis, either formal or informal, by a medical practitioner. However her social worker, asked if we would ask the pediatrician if the child had FAS. The doctor, after looking at the child's hands, said she hadn't got FAS. I must stress that no officially-recognized full screening/diagnostic test was done. I had asked also for the Vineland

Test (behavioural assessment tool in psychology) but they didn't run that, just an I.Q. test. There was then, and there still is little awareness of partial FAS and/or ARND in Ireland [foster parent].

Culture of drinking.

As the parents and professionals talked about their experiences with students with FASD, their conversations inevitably moved to the topic of drinking and the "culture of drinking" in Ireland. In the following quote, one participant speaks of aspects of the Irish drinking culture which may contribute to children being born prenatally exposed to alcohol.

Alcohol has been majorly tied into the Irish culture, and I think there's barely a family around who hasn't been affected by the touch of alcoholism in the family with one another, extended family members or whatever. And, for a good long time alcohol, beer, was also recommended for the production of milk, for breastfeeding, and so it just all went hand in hand, and nobody considered that there was anything abnormal about it.

Binge drinking on the college campus is rampant in this country. This is the only country in the EU where young girls go out with the intention to binge drink and to get pissed. They say that's the purpose of the night, and although they have some alcohol awareness programmes and the health initiative to "just say no," there is just no connection (being made) between binge drinking and unprotected sex.

Compounding both the lack of a formal process of diagnosing FASD and the culture of drinking is the lack of specific educational services for students with FASD in Ireland. The following section describes the educational provisions which the four students in this study with FASD received.

Educational services for students with FASD.

The four students in this study who were prenatally exposed to alcohol received varied education services. The boy who was 4 years old received no services and lived at home with his foster parents. The only girl with FASD in this study attended a second grade class in a neighbourhood Catholic school and received no specialized services. These two students did not receive any specialized services.

The other two students with FASD were brothers, ages five and nine years old. The five-year-old attended a junior classroom for half the day without special education supports and spent the other half of the day in a segregated special education programme. The nine-year-old boy attended a full-day special education classroom. These latter two students with FASD received special education services including: (a) small group instruction; (b) use of schedules; and (c) applied behavioural analysis. Although these two

boys' foster mother acknowledged the specialized services described above, she insisted on making the point that "the services which my sons receive are not specific to students with FASD, they are just (the standard) services which all special education students receive." As the following section suggests, the education provided for the students with ASD was more extensive than for the students with FASD.

"There are Individualized and Specialized Services for Children with ASD"

Parents of children with autism shared with us: (a) the early recognition and diagnosis of their child's disability; and (b) their satisfaction with the current services their child was receiving. Children with autism in this study had received the diagnosis of ASD before the age of three. Parents had noticed that their children were either not developing, or were actually losing skills, as one parent describes in the following interview transcript:

Around two and a half years he [their son] had some words, and then started to lose them, wasn't using them, like "mama, dada, baba, birdy," and they disappeared, and I began to notice he wasn't focusing on us at all.

Parents sought professional assistance to determine the cause of their children's delays. One mother shared that "I contacted a physician and they spent about a week doing all sorts of tests, just 'out-ruling' everything else, and then the paediatric neurologist diagnosed him with having autism."

Parents' and professionals' satisfaction with education services for their child with ASD.

Both of the students with autism who were a part of this study received individualized and specialized services in autism classes in segregated special education schools in Ireland. Parents caring for and professionals working with the students with ASD were satisfied with the services for students with ASD. As one parent shared: "I feel that my son is quite content there, very happy, probably because there's far less emphasis on an academic orientation."

Through observations and interviews with educators including special education teachers, special needs assistants, and principals, we learned that both of the students with ASD in this study received one-on-one support in classrooms where there were only two other children. Both students were taught by trained special education teachers, and both received support from qualified special needs assistants. The specialized interventions which these two students regularly received in class included: (a) Augmentative and Alternative Communication Systems (e.g., PECS); (b) Applied Behavioural Analysis (ABA); (c) sensory therapeutic programme; (d) Treatment and Education of Autistic and related Communications Handicapped Children Programme (TEACCH); (e) therapeutic listening;

(f) occupational therapy; (g) speech and language therapy; and (h) bowling, swimming and recreation.

Educators who worked with the students with autism in this study described the types of interventions and programs which the children received. One special education teacher described the programme she had set up in her classroom for students with ASD:

The TEACCH program layout of (my) classroom tries to encourage separate work stations for each child so that they've got their own place where they can have their own photographs (e.g. PECS) or things around them, so that they can sit there and do their own work. There is also a schedule so that they know what is ahead for them. Because, I find sometimes with the kids if they don't know what's ahead of them they get upset. We dabble a bit between TEACCH and ABA. We do a bit of ABA but not very much because we found we prefer the children to be social and not just one on one and we do record results and everything.

Our interviews with parents of children with FASD and ASD and the professionals involved in their lives revealed the differences between diagnosis and educational services for students with FASD and ASD. Children with ASD typically received a diagnosis early in life and individualized, intensive, and specialized services by a qualified teacher. Services for students with FASD were dramatically different. Parents (e.g., foster care) and professionals involved with the children with FASD in this study told us that (a) a diagnosis was difficult to obtain; and (b) specialized services in the schools and supports to families after school were not forthcoming.

From "No one listens" to "I've had to fight"

We asked the families of the both the children who experienced FASD and ASD to describe to us their experiences parenting their child and their hopes and dreams for the future. The theme "No one listens" described the accounts of parents of children with FASD; and the theme "I've had to fight" described the accounts of the families of children with ASD.

"No one listens:" Foster families of children with FASD.

All of the foster parents interviewed for this study spoke of their children's challenging behaviors. At four years old, Sean's behavior is worrisome and stressful for his foster mother. She describes the behavior in the following interview excerpt:

His tantrums are triggered by absolutely anything. I think the more attention you lavish on him, the more frequent are the bouts of temper, and it could be for absolutely any reason, and it happens like a bit like turning on a switch and it can last

anything up to an hour. He's never gone a whole day without having one.

He's way behind his year, and he can't retain any knowledge, not much. He has no concept of time, of today, yesterday, tomorrow or next week.

As a result of his behavior he no longer attends the local childcare setting; he now stays at home all day with his foster mother.

Another mother told us that she believes that foster parents of children with FASD deserve to be told that the child they are fostering has FASD. This foster mother believes "we need to know what to expect." Families told us that it seemed to them that "no one listens" and that they do "not receive the support or help that I need to deal with my child's behavior. Every day (name of child) curses at me, throws temper tantrums, and bullies us." The parents of students in this study expressed their frustrations about the lack of support they received and wondered whether or not the system was "pushing the children from family to family" rather than providing the necessary supports.

Frustrations with the lack of support.

The parents of the children with FASD were severely challenged by their children's behavior. Their (parental) frustrations increased when they discovered that supports for their children or for their family were not available. The voice of one child's mother was filled with anxiety and frustration as she shared:

Why is it so hard to get help? No one seems to be listening. And eventually when you are offered the help why are there such waiting lists? I know it is not the psychologist's fault. I know in [name of village] there's a shortage of psychologists and psychiatrists but now they're working on a backlog, we shouldn't have to wait for 6 months, a year. In the meantime what are we supposed to do? Or, somebody could tell us you need to start doing a, b, c; it would help down the road, you know? It's frustrating because I don't know what I should be doing with (name of son).

Sense of fear and powerlessness.

During our interviews with the families it seemed to us that their voices reflected fear. The following excerpt from an interview captures this sentiment:

As a foster parent yes you are afraid. The child can be taken away from you at any time.

You're afraid that if you speak up, and say that your child needs such and such then you will be looked at as a bad parent, that it is your fault. I worry every day that [name of child] will be taken away from me.

"I've had to fight:" Parents of Children with ASD

The power of litigation.

Early on in our conversations with professionals and parents of the students with ASD we were told about a precedent-setting legal court case in Ireland. Cathy Sinnott, a parent of a young man with autism, initiated court proceedings against the Irish Government. Ms. Sinnott argued that her son Jamie's right to an education had been denied by the Irish Government. As a result of this court case, some participants in this study felt that parents of children with ASD in Ireland are more powerful or empowered to seek services for their child than previously. The following quote from a parent of one student with ASD reflects her sense of empowerment.

Parents are not so inclined [as a result of the Sinnott case] to sit back and say "sure this is all we have, and that's it." They're more inclined to go out there and seek the service, or fight some bit for one. Cathy Sinnott is incredible.

Professionals too spoke of the services which students with ASD received as a result of the Sinnott case. As one principal shared "the reason why children with autism receive the services they do is because of litigation, the government is afraid [of law suits]."

The issue of fear of being involved in litigation regarding students with ASD dominated conversations with practitioners. Another principal shared that if "their parents are well informed they can get services too by litigation as well. They have certain entitlements but most of them (parents of other children with other disabilities) don't know their entitlements." Some parents have become, as one practitioner put it "well informed because they've gone and informed themselves." Other parents, she told us, "are not informed." As this principal explains in the following quote parents who are not informed of their options receive less services for their child: "Nobody comes chasing after them telling them you're entitled to this and to that."

Because they're afraid of people, the government. And they have had so many cases taken against them for denying people's rights, and you see autism is accepted now. If you have autism the doors will open, (whereas) if you have like a global developmental delay, like one of our children has, there is no box to put you in. Somebody, maybe a number of years ago opened a box and said autism children can now go in here. We'll give them x, y, z. But nobody has done that yet for fetal alcohol syndrome.

Parents' early role as advocate for their children.

Despite the fact that parents obtained a diagnosis for their child at an early age; services were not always forthcoming as one parent of a child with autism explained:

So we came home. And, at that time, in [name of county] there were no services for children with autism. We didn't have speech and language therapy services; we didn't have occupational therapy, nothing, really when I think of it, or play therapy of any kind.

The parents in this study who had children with ASD explained the instrumental role that they themselves had to assume in securing services for their children:

With the support of the school and the principal I got involved in setting up an autism unit within the primary school. And, [name of her son], was the first participant in that class with four other children from [the county]. And last year that evolved to become a fully-fledged unit with its own occupational therapy, speech and language therapy, sport and exercise science therapy and behaviour management.

Families universally shared what actions they took to secure services for their child. One mother told us "we started a fund raising drive in our area, and we raised well over 100,000." Another parent of a child with ASD shared that she felt that not one type of intervention or support worked for her child. It was, in a sense a "combination of everything. I can't say that I would just lean on one particular thing. I wouldn't. We found that bits of everything really work." It was the role of advocate and initiator which characterized parents of children with ASD. For example, one mother told us:

I wrote the proposal myself [to have a class for children with ASD], and after [her son] was diagnosed, and for the following couple of years, I would have gone to all the conferences, anything that was coming up, went to all of them about the TEACCH programme, I've attended all of them myself.

"Something Needs To Be Done"

The professionals interviewed in this study described their perspective on the provision of services for students with FASD and ASD. The theme of "Something Needs to Be Done," captures the reflections of the practitioner's recognition of the needs of students with FASD and the disparity between the services for students with FASD and for those with ASD. Additionally, practitioners believed that Ireland needs a policy for the provision of services for students with FASD and their families, which would include prevention efforts, training for practitioners, and support to families.

Disparity of services for children with FASD and ASD.

The voices of foster parents of children with FASD were often filled with frustration. As one mother describes below,

she was told "he's [her 4 year old son with FASD] not our responsibility."

September he is definitely going to school. They will have him assessed through an educational psychologist at school and he will be granted a special needs assistant because he needs one.

We've tried loads of different avenues to get psychological help, and to get him assessed, and all the avenues that we've tried have said no. "He's not our responsibility," "he's too young," "he should be in school," "the school won't take him so how can I?" We've tried certain charities. We've tried a psychologist in [name of centre], the centre for disturbed children, and we've tried schools and we've tried the health centre psychologist. They've all said no.

The professionals we interviewed revealed that students with ASD often receive 20 hours of specialized services a week; they are often in classes designed to meet their individual needs and they receive more attention and services than students with FASD or other disabilities. A principal of one elementary school described the phenomena in the following quote:

We applied for services (child with severe disabilities) and if you met [name of child] you would know why he needed these things more than any child that came in the school. We were refused. We took the month of September and ringing them every day, going to the TD, keeping on it and finally they gave in. But it was only for the fact that the child was not toilet-trained. And, they finally gave it (special needs assistant) to us because he needed toileting.

They're afraid of kids with autism. They're afraid they'll be brought to court. There is a culture of fear. It will probably take a court case to sort out fetal alcohol syndrome.

In addition to the recognition of the disparity between services for students with FASD and ASD, participants in this study shared with us their belief in the need for teacher training, and for supports to families.

Need For Teacher Training and Support for Families

Professionals echoed the voices of families and identified the need for training in the area of FASD for teachers and other service providers. As the following educators shared there is a low level of awareness of FASD and of the subsequent need for prevention, diagnosis, and intervention for the children and supports for families.

First step, I think we need to get people trained. People competent to diagnose it, and hand in hand

with that we have to have facilities available, but I don't think that facilities could come overnight. We have to do something. I think a lot of the children that probably, they are on the books here for example, they're diagnosed with ADHD and they are not getting services.

We need: Education. You know, you need to get it into the teacher-training colleges and into the Universities so they'll learn [professional].

Beyond the need for training for teachers, the participants in this study identified the need for prevention efforts to occur in Ireland. The following section highlights these issues.

Need for Prevention Activities

The interviews with professionals, including teachers, principals, psychiatrists, psychologists, and physicians consistently revealed their perspective on the immediate need for prevention efforts. FASD is a preventable disability they told us. Yet, as the following quotes reveal, Ireland's drinking culture, including binge-drinking by young women, places Ireland at high risk for FASD.

Prevention. Prevention. Definitely the most important part of the whole thing. They've [Irish government] got to get the message across, that drinking, no amount of drinking, if there is any possibility you might be pregnant not to drink, and that's not out there in the public domain.

In the following interview excerpt one psychologist describes the need for a media campaign:

Advertisement on the television, the media need to get hold of this idea. Irish society is very much centered on alcohol and I think in light of maybe women who drink that it is permissible. My experience here in Ireland would be that women would be, like, we can drink as much as the men, and we can be promiscuous as men, and the list goes on. What's happening right now is that women are binge drinking, getting pregnant, not even aware of being pregnant, continuing to drink [while they are pregnant].

DISCUSSION AND LIMITATIONS

The perspectives of these parents and professionals offer rich information on the needs of children with FASD and their families, as well as, the disparity between services for students with FASD and ASD. These perspectives are not meant to be representative of other families or practitioners in similar circumstances across Ireland. We have presented these findings because we feel that they provide insights regarding the needs of children whose lives have been touched by alcohol.

It is important to be explicit about the limitations of these data. First, the study presented the perspective of only six families and professionals involved in their lives. The inclusion of more families would have enhanced the findings. Furthermore, there were only 2 children with ASD. The inclusion of more children with ASD would have provided richer data. Second, the findings are based on a limited set of interviews conducted over an 8-month period of time. Data gathered over a more extended timeframe might provide better insights into more specific dynamics regarding the specific needs of the foster families. Finally, the data gathered represents only those perspectives that families and professionals felt comfortable or willing to share with a relative stranger, although the researcher had developed rapport with the families.

It was notable that the children in this study with FASD lived with foster families. As we interviewed families it was our impression that families of children with ASD tended to have a strong voice in the services for their children. On the other hand, the foster families we interviewed were tentative regarding their rights and ability to challenge either the education or social service system to secure needed resources which may have resulted in a difference in their voice.

It was very apparent that these foster families considered the child with FASD to be an integral part of their family life. Parents described a life dramatically impacted by both the challenging behavior of their child with FASD, as well as, the lack of support by the social service agencies. Despite their frustrations, the process of sharing their stories through the interviews seemed to give the families a feeling of hopefulness. They were hopeful that Ireland would respond to their needs and the needs of their child. They were hopeful for their child to receive an assessment and subsequent educational supports and services. They too, voiced their need for support to be able to deal with the learning and behavioral challenges of their child with FASD.

IMPLICATIONS FOR PRACTICE

The perspective of parents of children with FASD and ASD tell us much about the similarities and differences of these two groups of students. Both groups of parents of the children in this study spoke of their need for support to deal with their child's challenging behaviors. These parents have illustrated to us that problem behavior has had a tremendous impact on their family life and their ability to care for their child. It is critical for social service agencies to provide the support to adoptive, foster, and biological parents. These supports would include a broader system of assessment of challenging behaviors to address the needs of the child in both the home and the school environments. It is important to recognize the apparent similarities of support needs that both parents of children with ASD and FASD have related to their child's challenging behaviors.

Both sets of families spoke of the education needs of their child. Parents of children with ASD, were for the most part, satisfied with their child's educational programmes. Both of the parents of children with ASD in the study had qualified special educators working with their children. The children received individualized and specialized education services including: (a) applied behavioural analysis (ABA); (b) TEACCH programme; (c) sensory therapeutic programme; (d) music therapy; (e) therapeutic listening; (f) occupational therapy; (g) speech and language therapy; and (h) physical therapy. Researchers (NRC, p. 150) have identified the features of comprehensive programmes for students with ASD. These features are: (a) intervention begins early in life and is intensive in hours; (b) families are involved in the service provision; (c) staff is highly trained; (d) objective assessment of child's needs is ongoing; and (e) research-based procedures including generalizability and maintenance of skills are carefully planned. The educational programs of the students in this study who experienced ASD were reflective of evidence-based research and best practices.

The students with FASD did not receive (a) individualized and specialized services; (b) early diagnosis of their disability; or (c) evidence-based procedures as a part of their educational program. The lack of early identification of FASD and individual educational services, coupled with the lack of supports to families regarding their child's challenging behavior, places children with FAS at considerable risk (Streissguth, 1997). Streissguth (1997) has made us aware of children with FAS and their needs. She tells us "the stories of these individuals' lives were sad and shocking and it quickly became clear that these were not youth with mild disabilities who were fitting neatly into existing service for those with disabilities" (p.106). The following statistics on children with FAS are troubling: 90% have mental health issues; 60% experience disruption in school experiences; 60% get in trouble with the law; 50% experience confinement due to mental health, substance abuse problems and criminal activity (Streissguth, 1997).

Both sets of parents, those with children with FASD and those with ASD, spoke about the need for lifelong supports for their child. The following quotes, first by a mother of a child with ASD, and next by a foster mother of a child with FASD, describe their dreams and expectations for their child.

I would see [name of son] always in supervised supportive care. He would not be somebody who could at all be able to maintain or live independently. In this country, at this time, we have semi-voluntary organizations like [name of organization] that provide centres for the education for people with disabilities. So at least they could be on their own [mother of a child with autism].

Children with FASD, and my child, will have challenges their entire life. I do not see [name of child] living on his own. He has poor judgement and makes bad decisions. I am afraid that he will be taken advantage of by others and may get into trouble.

The major contribution of the current study is to highlight the needs of children with FASD and the potential lessons that may be learned from the successes of, and services for, children with ASD in Ireland. Children on the fetal alcohol spectrum would benefit from early identification of their disability; specialized education services by qualified educators; and supports to their families regarding challenging behaviour in the same way as children on the autism spectrum current do. Ensuring that services are provided for children with FASD is a responsibility which must be accepted by educators, service agencies, and policy-makers in Ireland.

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