



Fetal Alcohol Spectrum Disorders: The Impact on Public Education A Complicated And Pressing Public Health Issue With Major Implications For Schools





Amending the Individuals with Disabilities Education Act to Include Fetal Alcohol Spectrum Disorders (FASD) as a Specific Disability Category

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Introduction

Given the fact that the Centers for Disease Control estimates that up to 1 in 20 students may have a Fetal Alcohol Spectrum Disorder (FASD) (CDC Vital Signs, February 2016; American Journal of Preventive Medicine, November 2015), one might assume that adequate numbers of educators are being prepared across the U.S. to support this population of students in schools. However, there is evidence to the contrary and in one notable investigation conducted the data indicated that 61% of adolescents 12 years and older and 14% of children ages 6 - 11 on the fetal alcohol spectrum had a disrupted school experience (Streissguth et al. 2004). While some schools, agencies, and caregivers are making considerable efforts to improve education outcomes, overall educational systems nationwide are struggling to meet the needs of students on the spectrum. Children on the spectrum typically have special learning needs and a wide range of behavioral challenges that can have a significant impact on educational outcomes. These youth tend to have complex needs requiring support in a variety of areas including social, academic, behavioral, and life skills. As a result, there is need for more awareness on the impact of FASD and implications for the education system and the Individuals with Disabilities Education Act.

In order to bring awareness to this complex and urgent public health issue and the implications for schools around the U.S. we have developed this Issue Brief. This Issue Brief should be considered a “working document” for reference purposes. This project is a joint product that was undertaken by the Minnesota Organization on Fetal Alcohol Syndrome (MOFAS) and a subcommittee of affiliates of the National Organization on Fetal Alcohol Syndrome (NOFAS) including: NOFAS-Colorado, Double ARC, NOFAS-Ohio, the Texas Office for the Prevention of Developmental Disabilities, The Papillion Center, and the National Council of Alcoholism and Drug Dependence. The organizations have joined together in anticipation of the upcoming reauthorization of the Individuals with Disabilities Education Act. The national committee was charged with completing three tasks:

1. Review and respond to the rationale set forth under the U.S. Department of Education’s Final Regulations and Commentary regarding the implementations of the Individuals with Disabilities Education Improvement Act (IDEIA) of 2004, where the decision was made to decline adding Fetal Alcohol Syndrome as a specific disability eligibility category and the decision was made to decline to clarify Fetal Alcohol Syndrome as a specific example of a diagnosis under other health impairments (34 CFR Parts 300 and 301; Federal Register, 2006).
2. Develop, disseminate, analyze, and summarize findings on a national survey on issues related to Fetal Alcohol Spectrum Disorders (FASD) for individuals on the spectrum, caregivers, and professionals working in the educational field.
3. Develop a comprehensive Issue Brief to provide more information and guidance related to FASD and implications for IDEA to the federal government, law makers, professional organizations, the general education community, and the public to outline recommendations in order to improve education outcomes for this population.

The Issue Brief provides responses to key questions related to FASD and includes a summary of survey results and the analysis conducted by the committee. The overall analysis has resulted in the following recommendations from the national committee.



- Amend IDEA to require a referral for early intervention services for a child under age 3 identified as affected by prenatal alcohol exposure under Part C to improve results and providing needed services for infants and toddlers with an FASD and their families. The focus would be on measuring and improving outcomes with the goal that children impacted by prenatal alcohol exposure are ready for preschool and kindergarten.
- Amend IDEA to include a specific disability category for individuals with a diagnosis on the FASD spectrum for eligibility under Part B in order to more efficiently provide targeted and appropriate services to preschool and school age children that will be effective in achieving better educational outcomes for students on the spectrum.
- Amend IDEA Part D to include FASD to ensure technical assistance related to youth with an FASD to improve the capacity of schools to respond to the special needs of students on the spectrum.

What are the characteristics of our current population of children on the FASD spectrum?

Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term used for a spectrum of conditions caused by prenatal alcohol exposure. It is a spectrum condition and each diagnosis on the spectrum is based on the presentation of characteristic features; which are unique to the individual and may be physical, developmental, and/or neurobehavioral. Prenatal alcohol exposure is a complex public health issue that impacts children of all races and socio-economic backgrounds. Alcohol exposure during pregnancy is a major known cause of birth defects, neurodevelopmental impairments, and learning problems in the United States.

The spectrum includes the following four medical diagnoses:

- Fetal Alcohol Syndrome (FAS);
- Partial Fetal Alcohol Syndrome (PFAS);
- Alcohol-related neurodevelopmental disorder (ARND); and
- Alcohol-related birth defects (ARBD).

FASD diagnoses are based on several features: prenatal exposure to alcohol, growth deficits, characteristic facial anomalies, and central nervous system dysfunction (Astley 2004; Chudley et al. 2005; Hoyme et al. 2005). The diagnosis can have life-long implications for children including deficits in intelligence, attention, processing speed, executive functions, language functions, visual-spatial abilities, memory, adaptive functioning, social interactions, and academic achievement. While there is no single behavior profile that is always typical of an FASD diagnosis there are strong commonalities especially in the areas of learning challenges and social behaviors.

Research data and clinical observations have reported defects in multiple organ systems: nervous, cardiac, skeletal, renal, visual, auditory, immune, and other systems for children exposed to alcohol



prenatally. (O'Connor 2014). The most adverse outcome of prenatal alcohol exposure is the brain injury that occurs in all the medical disorders that fall under the FASD umbrella. Prenatal exposure to alcohol can result in a condition called microcephaly which means that the child will have a smaller overall brain size and volume reductions for some specific regions of the brain (e.g., the cerebellum, frontal lobes of the cortex, corpus callosum cortex, etc.). Prenatal alcohol exposure is the single most prevalent cause of intellectual impairment in children (Astley et al. 2000; Spohr et al. 1993). A summary of results from active case ascertainment studies funded by the National Institute on Alcohol Abuse and Alcoholism (NIAAA), in several different communities has estimated the prevalence of FASD in the United States to be at least 20 cases per 1,000 first graders. Children on the FASD spectrum often have special learning needs and a wide range of behavioral challenges that can have an impact on educational outcomes (May et al. 2009).

Brain injuries associated with FASD have major implications for students, families, and the education system. Some of the most documented impairments include problems with:

- Learning and memory
- Controlling emotions and impulsivity
- Generalizing knowledge
- Solving problems, organizing, and planning
- Understanding and following directions
- Understanding cause and effect
- Transitions and shifting attention
- Communication and socializing
- Understanding abstract thinking
- Adaptive functioning and life skills, including feeding, hygiene, counting money, telling time, and minding personal safety
- Sensory processing and integration

Alcohol consumption during pregnancy is a complex public health issue that impacts families across race, ethnicity, and socioeconomic status. The scientific and medical communities have long been aware of the risks associated with drinking during pregnancy. The first health advisory warning regarding the risks of alcohol consumption during pregnancy appeared in 1977. In 1989, the U.S. Congress began to require warning labels for alcohol to elevate awareness of the risks. The guidance from the Surgeon General, the American College of Obstetrics, the American Academy of Pediatrics, the Institute of Medicine and others is "there is no known safe level of alcohol use during pregnancy".

In spite of the guidance, alcohol use during pregnancy remains a known leading cause of preventable birth defects and developmental disabilities and learning problems (Stratton et al



1996). This reality demonstrates the complexity of addressing alcohol use during pregnancy. In the United States, approximately 50% of pregnancies are unintended. Therefore, it is possible for a woman to consume alcohol before she knows she is pregnant. For women struggling with substance use disorders the rate of unplanned pregnancies are even higher. For a woman living with Alcohol Use Disorders there are unique challenges related to alcohol consumption during pregnancy. Furthermore, another public health challenge is the fact that the community continues to receive mixed messages on the risks associated with drinking. Even medical providers contribute to this mixed messaging despite the guidance from their respective professional organizations and the Surgeon General.

Identification of FASD is an important first step in developing an appropriate education plan. Because the brain injury associated with an FASD is irreparable and permanent, intervention in the education context centers on schools recognizing the signs of the disability and providing external supports in a structured environment to accommodate students with an FASD. Despite its prevalence, FASD is often misunderstood and schools struggle to address students on the spectrum. Providing appropriate educational experiences for students with an FASD is a challenge. It further complicates matters because diagnoses on the FASD spectrum are not a recognized category under IDEA.

What are some of the implications of failure to address FASD in education?

When discussing FASD it is important to understand that a diagnosis on the spectrum and the resulting brain damage is a primary medical disability. Individuals on the spectrum are susceptible to secondary disabilities without the appropriate supports and interventions. Failures to ensure appropriate education accommodations can have an impact and play a role in the development of secondary issues and concerns. Not every individual on the spectrum will develop secondary concerns or disabilities. In fact, there are several protective factors including early intervention and appropriate educational support.

Following are some of the most common secondary conditions that have been found to be associated with FASD as part of a seminal investigation conducted by Anne Streissguth and her colleagues.

- **Mental Health Problems** affected more than 90% of individuals in the study. Commonly diagnosed mental health problems in individuals with an FASD included: Anxiety Disorders; Attention Deficit Disorder; Attention Deficit Hyperactivity Disorder, Conduct Disorder, Depression, Psychosis, and Suicide Threats or Attempts.



- **Disrupted Schooling** was a common occurrence, more than 60% of adolescents and 14% of children experienced disruption. About 53% of the adolescents with FASD had been suspended from school, 29% had been expelled, and 25% had dropped out. Certain behavioral symptoms associated with FASD may result in school disruptions. These behaviors include: disrupting class, learning difficulties, social difficulties, bullying and truancy.
- **Alcohol or Drug Use Disorders** is another common secondary condition. About 35% of individuals with an FASD in this study struggled with alcohol or drug use.
- **Contact with the Criminal Justice System** is another common issue. Sixty percent of adolescents and adults with an FASD in the study had contact with the justice system. Also, 14% of children had legal difficulties. The American Bar Association, states that “12.8 is the average age children with an FASD begin to have trouble with the law”. The study also noted that individuals who did not have disrupted school experiences were less likely to get in trouble with the law. The most frequent legal issues encountered included: shoplifting, running away, assault, crimes against property. The data in this study suggests a correlation between school disruption and getting into trouble with the law; which is supported by the data on the school-to-prison pipeline for students with disabilities.
- **Inappropriate Sexual Behavior** was exhibited by 49% adolescents and 39% of children with an FASD.
- **Challenges** were also identified in Dependent Living and Employment with 80% of the adults in the study unable to live independently and 80% had difficulty finding and maintaining employment.

None of these secondary issues exist in a vacuum. School systems play a critical role in identification of these students and with appropriate community and family support it is possible to redirect the educational trajectory of children on the spectrum, and can also play an important role in the prevention of secondary disabilities. A disrupted school experience for this population can be attributed to a number of factors, but there are several protective factors that lead to lower rates of these secondary concerns.

- **Early Diagnosis:** The earlier a child is diagnosed with an FASD, the earlier interventions can begin and a diagnosis by age 6 is optimal.
- **Involvement in Special Education and Social Services:** The brain injury caused by prenatal alcohol exposure can lead to learning difficulties and challenging behaviors. Special education can address the unique needs of children on the spectrum. Early involvement with special education and access to social services can help prevent secondary concerns of school disruption.
- **Stable Home Environment:** All children benefit for a loving, nurturing, and stable caretaking



environment. Individuals with an FASD may be more sensitive to disruptions to their routines, transient situations, and harmful relationships.

- **Absence of Violence:** Individuals on the spectrum who live in an environment without violence are less likely to become involved in violent activities.

The failure to understand this neurological disorder and address the effects of FASD adequately imposes a severe burden on the community overall. This speaks to the importance of diagnosis, early intervention, appropriate school supports at the earliest possible stages of child development. Teachers, paraprofessionals, counselors, and parents working together can give a child on the FASD spectrum a good schooling experience. A successful educational experience can lay the foundation that will help the individual with an FASD build a successful life.

What promising and evidence based practices have been identified for this population of students on the FASD spectrum?

There is a need for more research and identification of evidence-based practices for individuals on the FASD spectrum. However, when you consider that Fetal Alcohol Syndrome was identified in the United States in 1973 it is a reminder that this a relatively young area of research. Training for schools and caregivers to help them understand FASD is a critical aspect of effective interventions. An assessment under Part C of IDEA can be a good starting point for screening for young children.

Currently there are some research-based, validated interventions for people with an FASD that have been developed and implemented in communities around the U.S. There are also several promising and emerging practices. Most are focused on addressing behavioral, cognitive, and academic skills, as well as adaptive functioning. There are also several in-progress interventions that are currently being studied including nutrition and supplement interventions that are potential treatments of the future.

Listed below are some of the evidence-based intervention programs specific managing and working with students on the FASD spectrum.

- The Math Interactive Learning Experience (MILE) Program: Children with FASD often have difficulty with math skills. Problems in this area result from early and ongoing difficulties with visual/spatial learning, working memory, and self-regulation. Without the proper foundation, they struggle to master mathematical skills and reasoning which impacts important academic and daily functioning. The Fetal Alcohol and Drug Clinic at the Marcus Institute in Atlanta, with the support of the Centers for Disease Control developed a model program suitable for children, ages 3 to 9



years old that are at risk for math problems. The Clinic developed a model for educating parents and teachers about FASD and for tutoring children. This involved creating teaching methods and manuals for caregivers, teachers and tutors focusing on FASD facts, Caregiver Advocacy, Behavior Management, and Mathematics. Investigators found the children who received the 6-week intervention showed significant improvement in math skills and in handwriting skills in comparison to randomly assigned group who did not. Parents who participated reported that their child's behavior had improved significantly.

- **Executive Functioning Training:** The Children's Research Triangle in Chicago developed this project to teach behavioral awareness, self-control and improves executive functioning skills, such as memory, cause and effect, reasoning, planning, and problem solving. A research study evaluated this type of training and found that children had significant improvement in effective functioning skills.
- **The Good Buddies Program:** The Good Buddies program was developed with the University of California. The social deficits that are often involved with FASD can have a significant negative impact on children who are not able to make or keep friends. Without peer social support, these children are more likely to experience behavioral and emotional difficulties. Having at least one or two close friendships can act as a buffer for children against low self-esteem, depression, and anxiety. Good Buddies was developed to give children with an FASD social skills training to help make this process easier. Children and parents attend 12 separate 60-75 minute sessions concurrently.
- **Parents and Children Together (PACT):** The PACT program was developed with the Children's Research Triangle in Chicago. One of the primary struggles children on the FASD spectrum face are deficits in self-regulation and executive functioning. These deficits can exist in the form of poor impulse control as well as a lack of intrinsic motivation to start or complete tasks, poor memory, and inattention. The program was designed to help children and their parent learn strategies to cope with these difficulties. The parents focus on education about FASD as the children learn body and emotional awareness, planning skills, emotion labeling, self-monitoring and self-regulation, memory building, self-esteem development, to compensate for weaknesses, and to build upon existing skills and strengths. The program consists of 12 group therapy sessions.
- **Language to Literacy Program:** A classroom-based program provides instruction to improve receptive and expressive language skills as well as early literacy skills. The program is a combination of language therapy, phonological awareness, and literacy training administered by a speech therapist. The intervention was designed for 9 and 10 year olds. The program was administered for half an hour twice a week by an experienced speech and language therapist. A total of 38 hours of therapy over a 9 month period in a group classroom settings with 19 hours of language therapy alternating with 19 hours of phonological awareness. The program is focused



on training in phonological awareness and acquisition of other pre- and early literacy skills necessary for competency in reading and spelling.

There are also a number of emerging and promising practices as well for the population including the following.

- **Families Moving Forward (FMF):** FMF is a scientifically validated program developed by the University of Washington focused on positive parenting intervention that provides caregiver-focused education, support, and behavioral consultation. Objectives of the FMF Program include helping a parent better understand the effects of prenatal alcohol exposure, their child's skill profile, and advocacy techniques. Additional objectives include improving caregiver attitudes, self-reported parenting practices, and self-care. The ultimate goal is to reduce a child's disruptive behavior. The FMF Program helps families boost their progress in a positive direction, helping to increase caregiver optimism and reduce the chance their children will develop additional disabilities later in life. The caregiver meets with the FMF specialist for a series of coaching sessions addressing issues involved with raising children with FASD. Weekly sessions last approximately 90 minutes and the overall program lasts 9-11 months. An alternative 60-minute, weekly format is now being developed.
- **The Interagency Collaborative FASD Project:** The Minnesota Organization on Fetal Alcohol Syndrome, along with Minneapolis Public Schools and the University of Minnesota FASD Program began an interagency collaboration to address many of the issues surrounding the needs of children with an FASD in educational settings. It was based on the need for more community, medical, and school partnership to address FASD in education. The program implemented a screening program for incoming kindergarten students. The students with positive screens were referred for an FASD diagnostic assessment. Students identified on the FASD spectrum had clinicians familiar with their case as members of the IEP Team. This project also provided district-wide training for teachers to be better prepared to work with students.
- **Preparing Future Educators Collaboration:** The Minnesota Organization on Fetal Alcohol Syndrome has a long-standing collaboration with Augsburg College focused on preparing future teachers to work with students impacted by prenatal alcohol exposure. The collaboration includes training on understanding the disability, identifying red flags, and educational strategies for improving outcomes. The future educators are then paired with families to interview families, get to know students with an FASD, and participate in a school observation.
- **Southside Family Nurturing Center Collaboration:** In partnership with the Minnesota Organization on Fetal Alcohol Syndrome, Southside is screening all the kids in their therapeutic preschool program for prenatal alcohol exposure. Children identified and their families will work with staff



on a FASD-informed case management plan. The children identified will be referred for an FASD diagnostic assessment and will receive 6-months of transition support services as the children transition from pre-school to kindergarten.

- **MOFAS YouthAct Self-Advocacy Peer Network:** The peer network is youth led and adult supported. The program is designed for transition age youth 12 – 25. The network receives leadership and selfadvocacy training and works to improve outcomes in transition systems for individuals with an FASD. These youth and young adults are prepared to play an active role in their education and to self-advocate for appropriate services.
- **United States Fire Administration (USFA) Kids Program:** Individuals with disabilities are at greater risk of harm and can benefit from increased practices and specialized safety training. The project uses a virtual reality computer game to teach fire safety skills to children diagnosed with Fetal Alcohol Syndrome. The goal is to generalize these skills to a real world simulation.

Addressing the commentary from the most recent IDEA reauthorization that is related to FASD.

In the most recent reauthorization of IDEA, there was public comment recommending adding a disability category for children with Fetal Alcohol Syndrome. Below we address the comments and discussion from the most recent reauthorization related to FAS.

Child With a Disability (§ 300.8) General (§ 300.8(a))

Comment: Several commenters stated that many children with fetal alcohol syndrome (FAS) do not receive special education and related services and recommended adding a disability category for children with FAS to help solve this problem.

Discussion: We believe that the existing disability categories in section 602(3) of the Act and in these regulations are sufficient to include children with FAS who need special education and related services. Special education and related services are based on the identified needs of the child and not on the disability category in which the child is classified. We, therefore, do not believe that adding a separate disability category for children with FAS is necessary to ensure that children with FAS receive the special education and related services designed to meet their unique needs resulting from FAS.

Changes: None.

We intend to recommend during the next reauthorization period that FASD be identified as a separate and distinct class entitled to benefits. We are not requesting a change in law so much as a clarification. There is precedent for this clarification. In 1990, both Autism and Traumatic Brain



injury were added as specific eligibility categories under IDEA even through the argument could be made that children with these disabilities could access special education and related services under existing categories. In fact, many students with Autism were previously served under classifications, such as “mental retardation” and students with traumatic brain injuries were served under “other health impaired” or under “specific learning disability” prior to the 1990 amendments. The current prevalence data on FASD in U.S. school children is estimated to be higher than rates of Autism Spectrum Disorders. Like Autism, FASD is a complex public health issue and spectrum disorder that has serious implications for schools across the U.S. The clarification of Autism Spectrum Disorders under IDEA as a played a critical role in elevating the profile of students on the Autism spectrum and ultimately the disability has become a major issue in the education context. As a result, states have established autism-specific initiatives under IDEA, across the nation. Many of these focus on professional development and technical assistance. There is a precedent for this level of clarification with both Autism and Traumatic Brain Injury. And from a public health and prevalence perspective there is a pressing need to elevate the issue of FASD and special education implications.

Other Health Impairment (§ 300.8(c)(9))

Comment: We received a significant number of comments requesting that we include other examples of specific acute or chronic health conditions in the definition of other health impairment. A few commenters recommended including children with dysphagia because these children have a swallowing and feeding disorder that affects a child's vitality and alertness due to limitations in nutritional intake. Other commenters recommended including FAS, bipolar disorders, and organic neurological disorders. Numerous commenters requested including Tourette syndrome disorders in the definition of other health impairment because children with Tourette syndrome are frequently misclassified as emotionally disturbed. A number of commenters stated that Tourette syndrome is a neurological disorder and not an emotional disorder, yet children with Tourette syndrome continue to be viewed as having a behavioral or conduct disorder and, therefore, do not receive appropriate special education and related services.

Discussion: The list of acute or chronic health conditions in the definition of other health impairment is not exhaustive, but rather provides examples of problems that children have that could make them eligible for special education and related services under the category of other health impairment. We decline to include dysphagia, FAS, bipolar disorders, and other organic neurological disorders in the definition of other health impairment because these conditions are commonly understood to be health impairments. However, we do believe that Tourette syndrome is commonly misunderstood to be a behavioral or emotional condition, rather than a neurological condition. Therefore, including Tourette syndrome in the definition of other health impairment may help correct the misperception of Tourette syndrome as a behavioral or conduct disorder and prevent the misdiagnosis of their needs.



Changes: We have added Tourette syndrome as an example of an acute or chronic health problem in §300.8(c)(9)(i).

There were recommendations from several commenters requesting that Fetal Alcohol Syndrome and other medical conditions be added to the list of acute or chronic health conditions in the definition of other health impairments. The decision was made to decline to include Fetal Alcohol Syndrome with the rationale that is commonly understood to be a health impairment. However, Tourette Syndrome was included because of misperceptions of Tourette Syndrome as a behavioral or conduct disorder.

Unfortunately, FASD like Tourette Syndrome is often misunderstood as a mental health or behavioral or conduct disorder. Within our nationwide survey summarized later in this document it becomes clear that an FASD diagnosis is not commonly understood as a health impairment. The disability is often misunderstood due to overlapping characteristics of other diagnoses. Currently with specific category or clarification under other health impairments there are students struggling with misdiagnosis of their needs. Furthermore, there is no acknowledgement that FAS is only one diagnosis on the spectrum.

Highlight the findings of the national survey related to IDEA and FASD.

The committee created and conducted a survey “Special Education Survey and Fetal Alcohol Spectrum Disorders” between June 1, 2016 through June 30, 2016. The survey was conducted online. The current data summarized is through June 13, 2016. The purpose of this survey was to:

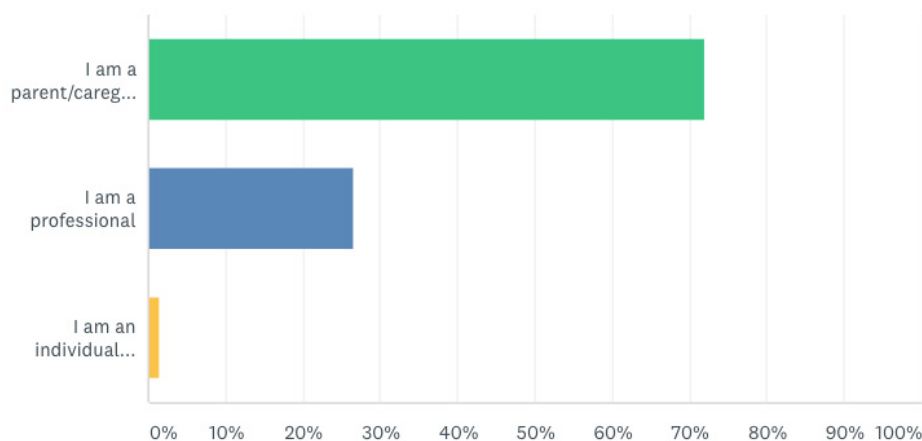
- Gather information from parents of students on their experience regarding IDEA and collect their suggestions for the next IDEA reauthorization.
- Gather information from overall education-related professionals for the next IDEA reauthorization.
- Gather information from adult individuals on the FASD spectrum on their experience with IDEA and collect their suggestions for the next IDEA reauthorization.

As of June 16, 2016, we had received 867 responses. In total, we received 669 complete responses with a survey completion rate of 77%. This summary is based on the complete responses received as of the date above.



Parent and Caregiver Summary

We received 481 responses from parents and caregivers from around the U.S. on the survey and their responses represented 71.9% of the total responses. This is critical because the intent of the IDEA is to promote family and school partnerships. However, historically the trend is that parental feedback and comments have been underrepresented in previous IDEA reauthorizations.

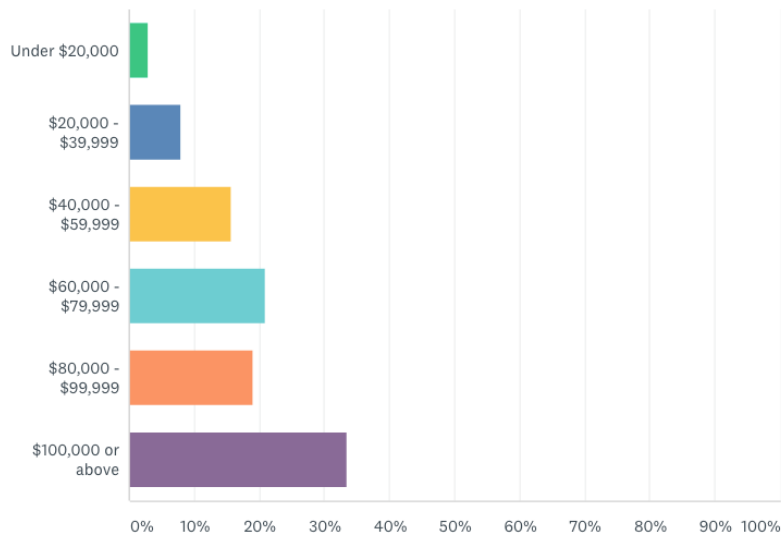


The vast majority of parent responses (79%) were from individuals identifying themselves as the mother of an individual on the FASD spectrum. Fathers represented 3.74% of the responses, foster parents made up 3.12%, and legal guardians were 4.78%. Individuals identifying as other were 9.36% of the responses and included classifications such as step parent, grandparent/adoptive grandparent, Relative caregivers, and adoptive parent. The parents and caregivers that responded represent 43 states. The top five numbers of responses from states participating in the survey include:

- Minnesota – 57 responses
- Ohio – 53 responses
- California – 49 responses
- Michigan – 47 responses
- Texas – 23 responses

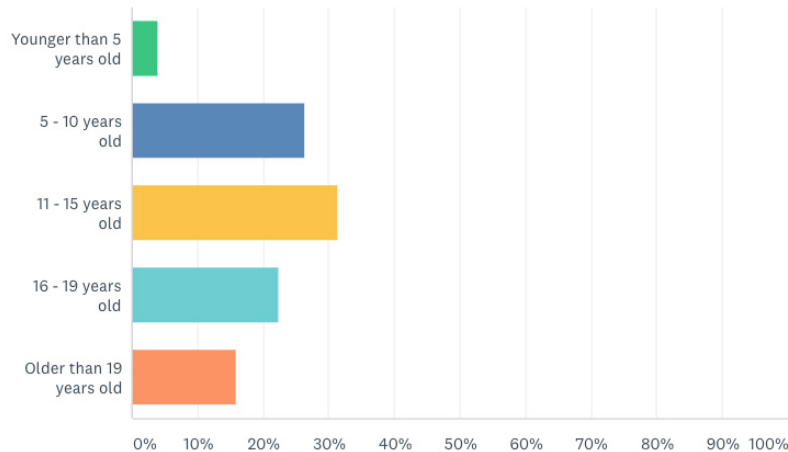


The responses collected included individuals with diverse annual incomes. The majority of respondents (33.06%) indicated a household income of \$100,000 and above.



Slightly over 60% of the responses (60.5%) were in regards to an individual on the spectrum identified as male.

The majority of individuals (31.39%) on the spectrum were identified as being between the ages of 11 years to 15 years of age.





The majority of parents (89.60%) responding identified their child as being adopted.

The majority of parents (68.19%) identified their child as Caucasian/European American. Approximately, 8% used the other category, which included responses such as: Russian, Brazilian, Bi-racial, Ethiopian, Central Asia, Roma, and Unknown.

ANSWER CHOICES	RESPONSES
Younger than 5 years old	3.90% 21
5 - 10 years old	26.39% 142
11 - 15 years old	31.41% 169
16 - 19 years old	22.30% 120
Older than 19 years old	15.99% 86

The primary diagnosis identified breakdown is as follows:

- 43.07% Fetal Alcohol Syndrome
- 9.52% Partial Fetal Alcohol Syndrome
- 25.54% Alcohol Related Neurobehavioral Disorder
- 1.52% Alcohol Related Birth Defects
- 26.19% A diagnosis on the FASD spectrum is suspected, but not confirmed

School discipline issues were also very common among the caregivers surveyed and 369 respondents indicated that their child had been disciplined at school in one or more of the following ways.

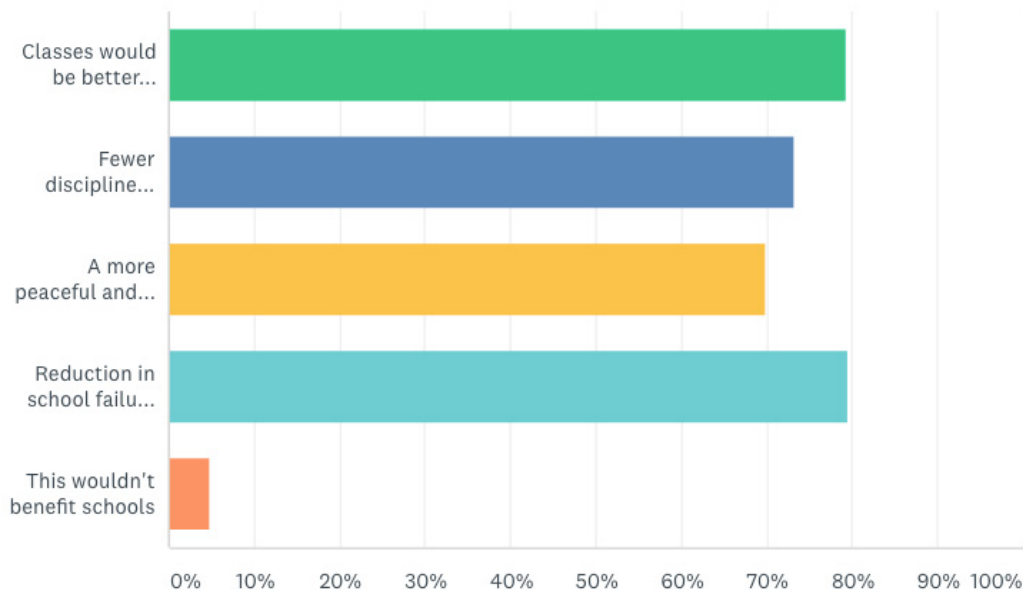
ANSWER CHOICES	RESPONSES
Time out/De-escalation room	61.15% 329
Restraint/Seclusion	25.84% 139
Sent out of the room	54.09% 291
In-school suspension	35.69% 192
Out-of school suspension	38.10% 205
Expulsion	6.88% 37
N/A	23.23% 125



Also, 40.62% of caregivers reported that their child had experienced interactions with law enforcement and the criminal justice system.

While 90.44% of caregivers responded that their child has or had an IEP, 60.94% of caregivers reported that not all of the concerns had been addressed about their child's development and education. Furthermore, the responses also demonstrated a lack of consistency in how the school approached eligibility for special education. The commentary in the recent regulations suggested that it was clear that Fetal Alcohol Syndrome fell under "other health impairment". However, the survey shows that 59.7% of the respondents identified that their child was being served under other disability categories and not under other health impairment. Also, only 7.78% of parents reported that they felt the category used to qualify their child was relevant. The vast majority of parents reported the categories used were misleading, vague, did not reflect the needs of their child, only reflected a segment of the disability, and it did not provide accurate guidance on how to work with their child. Further, 94.47% of respondents felt the lack of recognition of FASD under IDEA created a barrier to their child obtaining appropriate educational accommodations. Also, 93.35% of caregivers reported that the lack of an appropriate category for children with an FASD is discriminatory for children with an FASD and/or opens opportunity for marginalization.

The vast majority of caregivers reported their belief that inclusion of FASD under IDEA would yield benefits for schools specifically.





The respondents also indicated the following benefits.

ANSWER CHOICES	RESPONSES
▼ The child would be more likely to receive an education that is actually appropriate education based on needs	89.96% 484
▼ The child would be less frustrated, happier, and with fewer behavior issues	85.87% 462
▼ Reduction in overall family stress	80.86% 435
▼ A reduction in strategies used that actually exacerbate the challenges that children with an FASD already face	83.64% 450
▼ I do not see any benefits for students with an FASD or their families	1.49% 8

Over, 90% of caregivers in the survey reported that in their opinion students with an FASD have a more difficulty time obtaining appropriate education accommodations as compared with other disabilities. They also reported high rates of frustration with navigating the special education system for their child on the spectrum. Parents also overwhelmingly indicated (98.74%) that a child's school experience plays a contributing factor to the development of secondary disabilities and issues.

Education Professional Summary

We received 177 complete survey responses from professionals from various backgrounds in 21 states.



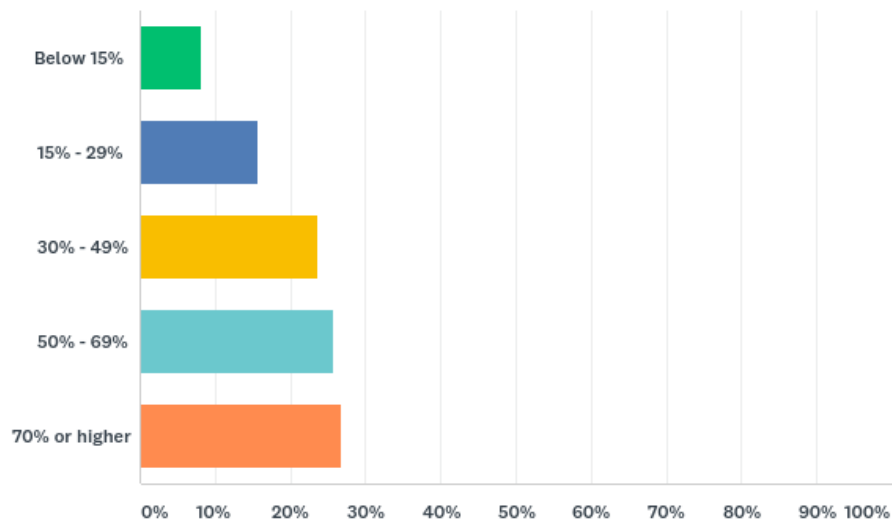
CENTER FOR FASD
JUSTICE & EQUITY

ANSWER CHOICES	RESPONSES
▼ Advocate	18.09% 36
▼ Attorney	2.01% 4
▼ Case Manager	5.53% 11
▼ Early Childhood Educator	1.51% 3
▼ FASD Consultant	5.03% 10
▼ Guidance Counselor	1.01% 2
▼ Higher Education	3.52% 7
▼ Medical Doctor	3.52% 7
▼ Occupational/Physical Therapist	1.01% 2
▼ Paraprofessional	1.51% 3
▼ Psychologist	9.55% 19
▼ School Administrator - Elementary	2.01% 4
▼ School Administrator - Middle School	0.00% 0
▼ School Administrator - High School	0.50% 1
▼ Social Worker	9.55% 19
▼ Special Education Teacher	4.52% 9
▼ Speech Language Pathologist	1.51% 3
▼ Teacher - Elementary	1.01% 2
▼ Teacher - Middle School	0.00% 0
▼ Teacher - High School	1.01% 2
▼ Other (Please Specify)	Responses 27.64% 55



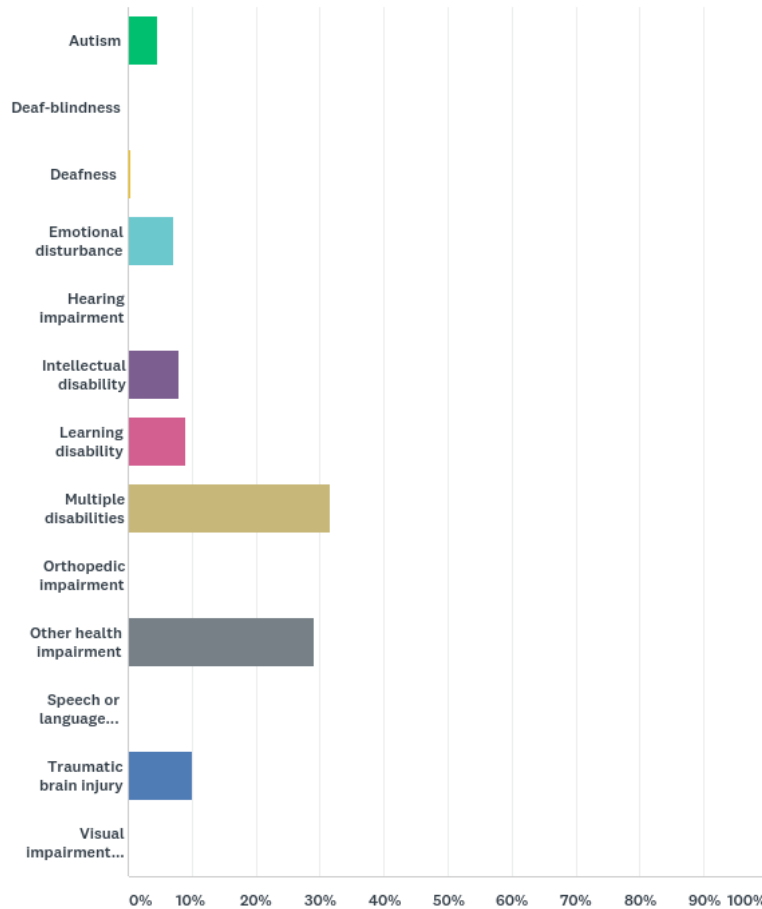


The majority of professionals responded that the vast majority of children with an FASD struggle to qualify for special education services.





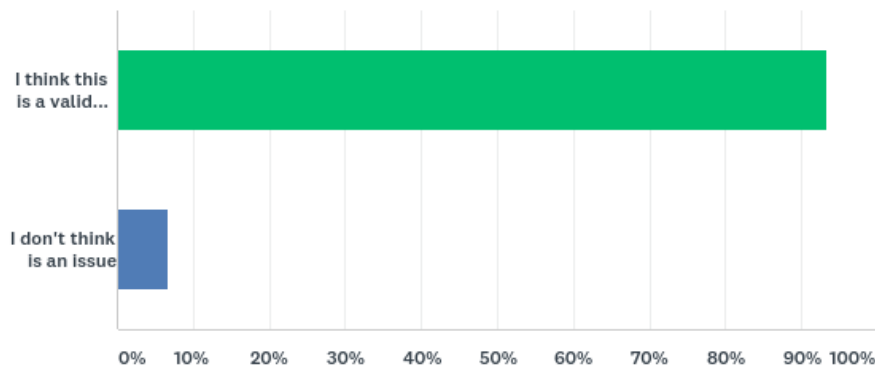
We asked the professionals in their opinion which of the special education categories best met the educational needs of students with an FASD. The responses varied as follows:



The vast majority of the professional respondents (98.8%) opined that FASD not being recognized under IDEA creates a barrier for students on the spectrum to obtain an appropriate education. They also overwhelmingly reported if FASD was recognized as a qualifying category that schools would see benefits ranging from improved classroom management, fewer discipline issues, and a reduction in school failures and dropouts. Also, 99.44% of professionals believed recognition of FASD as a category would yield positive results for families as well ranging from increased success school to reduction in overall family stress.



Over 80% of respondents reported that students with an FASD have a more difficult time obtaining appropriate education accommodations compared to other children with disabilities. The professionals surveyed also believed the lack of an appropriate category for children with an FASD is discriminatory and/or creates opportunities for discrimination or marginalization.



The majority of the professionals (98.87%) that responded to the survey were of the opinion that a child’s school experience is a contributing factor to the development of secondary disabilities and issues. Also, the same number of respondents acknowledged in their answers that it is common for parents frustrated with public schools to choose alternative educational methods for their child on the spectrum. The professionals surveyed also were of the opinion that school failures and drop outs are real implications and 28.81% of professionals estimated that 50% - 69% of students on the spectrum fail or drop out.

Individuals on the Spectrum

We had 11 responses from 7 states from adults on the spectrum that reflected on their various school responses. Eight of the responses were from individuals identifying as female and 3 individuals that identified as male. The race/ethnicity breakdown was as follows.

Eight of the individuals reported that they were adopted. Six of the individuals reported that

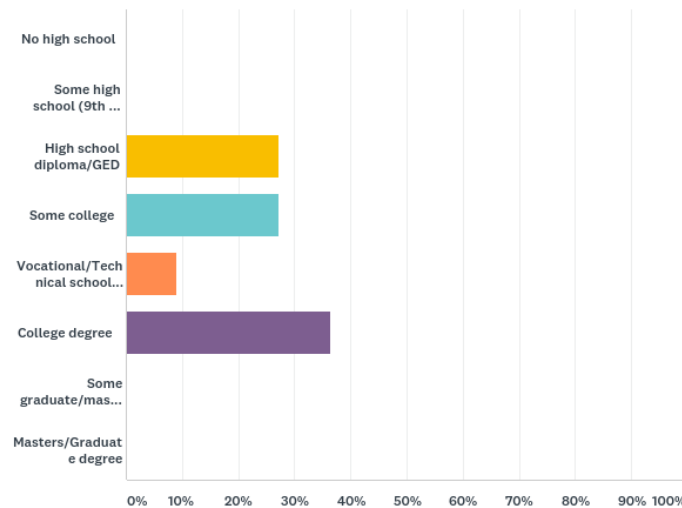
ANSWER CHOICES	RESPONSES
▼ African American	27.27% 3
▼ Asian/Pacific Islander	0.00% 0
▼ Caucasian/European American	63.64% 7
▼ Latino/Hispanic/Chicano	0.00% 0
▼ American Indian	18.18% 2
▼ Other (Please Specify)	Responses 0.00% 0





their diagnosis was Fetal Alcohol Syndrome and 6 reported that a diagnosis was suspected. One respondent had a conflicting response. The 11 individuals surveyed shared the highest level of educational attainment and 36.6% had a college degree.

Five of the individual respondents reported that they had interactions with the police.



ANSWER CHOICES	RESPONSES
Police called	9.09% 1
Police warning	18.18% 2
Arrested	36.36% 4
Charged with misdemeanor or felony	45.45% 5
Served time in jail	18.18% 2
Served time in juvenile detention	0.00% 0
No	54.55% 6
Yes, but it is not listed above (Please state in box below)	Responses 0.00% 0



Five of the respondents indicated that they had been identified by their school as needing special assistance or accommodations. Three reported they were not identified as needing special assistance or accommodations and 3 did not know if they had been identified. The majority of respondents were also of the opinion that FASD not being recognized under IDEA was a barrier to obtaining appropriate educational accommodations.

	NOT AT ALL	A LITTLE	SOMEWHAT	QUITE A BIT	A LOT	TOTAL
In your opinion, for children with an FASD, how big of a barrier is this in obtaining appropriate education accommodations?	9.09% 1	9.09% 1	0.00% 0	27.27% 3	54.55% 6	11

The individual responses also reported their belief that inclusion of FASD under IDEA would result in benefits for schools as well.

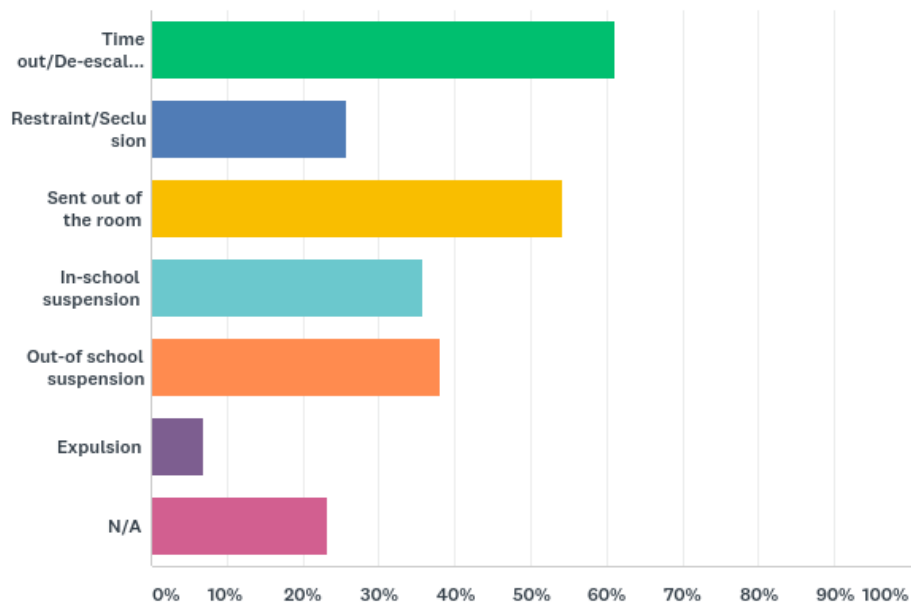
ANSWER CHOICES	RESPONSES
Classes would be better managed and all children would learn better	79.37% 427
Fewer discipline issues	73.23% 394
A more peaceful and productive school atmosphere	69.89% 376
Reduction in school failures and dropouts	79.55% 428
This wouldn't benefit schools	4.83% 26

They also reported benefits for students and families ranging from receiving an appropriate education, less frustration, less behavioral issues, and a reduction in overall familial stress. Also, over 80% reported that there are implications related to discrimination and marginalization due to the lack of an appropriate category for students on the spectrum. Those surveyed also reported that students on the spectrum have a more difficult time obtaining appropriate educational accommodations compared to other children with disabilities. The respondents also indicated their belief that school experience is a contributing factor to developing secondary disabilities.





School discipline was common among the respondents and eight of the students reported they had been disciplined in one or more of the following ways.



Summary



CENTER FOR FASD
JUSTICE & EQUITY

In closing, we will share the perspective of a young-adult on the spectrum to illustrate the need for FASD to be recognized under IDEA. The individual shared, "I struggled all throughout school. It was tough to stay motivated and focused on understanding lessons taught along with the rest of the class. I felt I learned at a different level and pace, but never understood why, there was no label to put it on it other than people thinking you are just bad or stupid. Kids have a better chance of success if they have academic needs being met based on their learning style due to having a disorder."

FASD is a complex public health issue that has implications for students, families, and the national educational system. The current research demonstrates the disability is common and as the CDC reports up to 1 in 20 students in the U.S. may be on the spectrum. Despite the prevalence, the public health issues, and the implications for schools families across the United States are facing barriers and challenges to navigating special education services for their children with an FASD. As a result, there are children on the spectrum that are receiving the education to which they are entitled.

The failure to identify FASD as an eligibility category creates an environment of inconsistency. While the commentary from the previous IDEA reauthorization stressed that FAS was commonly known and understood to be a health impairment the reality is that schools are not grasping this disorder as a health impairment consistently. As a result, many families are frustrated and concerned about their child's ability to receive an appropriate education. They are also concerned that schools do not have an understanding of FASD and are over reliant on school discipline as a result. The fact is that regardless of any form of discipline applied to a child on the spectrum that punishment is not going to reverse the brain damage associated with FASD. Furthermore, as the respondents across our survey for families, professionals, and individuals on the spectrum indicated that school experience plays a role in the development of secondary disabilities. The national committee strongly believes by recognizing and appropriately addressing FASD in education we can disrupt the trend towards secondary disabilities and disrupt the school-to-prison pipeline for students on the FASD spectrum. FASD needs to be addressed in education. It is a matter of justice.

