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## Prevention of Secondary Conditions in Fetal Alcohol Spectrum Disorders: Identification of Systems-Level Barriers

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### Abstract

**Objective**—Fetal alcohol spectrum disorders (FASD) impact 2 to 5 percent of the U.S. population and are associated with life-long cognitive and behavioral impairments. Individuals with FASD have high rates of secondary conditions, including mental health problems, school disruptions, and trouble with the law. This study focuses on systems-level barriers that contribute to secondary conditions and interfere with prevention and treatment.

**Methods**—Using a phenomenological methodology, semi-structured interviews and focus groups were conducted with parents of children with FASD and service providers. Data were analyzed using a framework approach.

**Results**—Participants emphasized the pervasive lack of knowledge of FASD throughout multiple systems. This lack of knowledge contributes to multi-system barriers including delayed diagnosis, unavailability of services, and difficulty qualifying for, implementing, and maintaining services.

**Conclusions**—FASD is a major public health problem. Broad system changes using a public health approach are needed to increase awareness and understanding of FASD, improve access to diagnostic and therapeutic services, and create responsive institutional policies to prevent secondary conditions. These changes are essential to improve outcomes for individuals with FASD and their families and facilitate dissemination of empirically supported interventions.

### INTRODUCTION

Prenatal alcohol exposure is the leading preventable cause of developmental disabilities in the U.S. The term fetal alcohol spectrum disorders (FASD) represents a continuum of life-long disabilities and includes diagnoses of fetal alcohol syndrome (FAS) and alcohol-related neurodevelopmental disorder (ARND) [1]. Alcohol causes structural and functional alterations to the brain during fetal development, and is associated with impairments in cognition and behavior [2]. The prevalence of FASD has been estimated to be 2 to 5 percent of the U.S. population, although only a small fraction of these individuals are recognized and receive an appropriate diagnosis [3].

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The neuropsychological profile of individuals with FASD can vary widely depending on the dose and pattern of prenatal exposure and other maternal and environmental characteristics [4]. However, a number of domains tend to be most commonly affected across individuals and include general intellectual functioning, complex information processing, attention, learning, and executive function [5-6]. Social and behavioral problems are also common and can include hyperactivity, social skills deficits, poor adaptive functioning, and externalizing behavior [6]. These areas of impairment are generally consistent with findings from imaging studies, which show disproportionate alterations to specific regions of the brain [7].

Rates of secondary conditions are high in individuals with FASD and increase dramatically in adolescence and adulthood [8-9]. Specifically, 94% of individuals with FASD have experienced at least one mental health problem during their lifetime, 61% have a disrupted school experience (i.e., suspended, expelled, dropped out), 60% have encountered trouble with the law, 50% have been confined (e.g., jail, inpatient psychiatric treatment), 49% have inappropriate sexual behaviors, and 35% have alcohol or drug problems [8-9]. The factors considered most protective against the development of secondary conditions in this population include living in a stable and nurturing home, not having frequent changes of household, early diagnosis, provision of developmental disabilities services, and not being a victim of violence. In contrast, individuals with an FASD diagnosis *other than* FAS, an IQ *greater* than 70, and a higher level of behavior problems are at higher risk for secondary conditions [8-9].

Several interrelated mechanisms may contribute to the development of secondary conditions in individuals with FASD. At the interpersonal level, people often misinterpret the primary disabilities of individuals with FASD as willful behavior (e.g., “won’t” vs. “can’t”). When the behavior is misinterpreted, inappropriate interventions or punishments are used and the individual is left feeling frustrated and discouraged. The repetition of this pattern over time and in multiple settings can contribute to individuals engaging in maladaptive behaviors to cope with the stress and frustration of not being understood or supported [10]. Secondary conditions arise from these maladaptive behaviors. Systems-level factors are also thought to contribute to the development of secondary conditions. Lack of knowledge about FASD and an understanding of how it presents in children and adults contributes to the misinterpretation of behaviors. A large national study [11] identified that many providers have inadequate training in FASD and community education (e.g., warning signs) about the dangers of drinking during pregnancy is lacking. Many parents and providers in the national study also complained of the lack of appropriate diagnostic and intervention services for individuals with FASD in every system of care. Without adequate understanding and supports for individuals with FASD, high rates of secondary conditions are likely to continue.

Secondary conditions place a large emotional burden on individuals with FASD and their families. High levels of stress are common in all types of families raising children with FASD due to the constant vigilance required to manage children's cognitive and behavioral challenges [12-16]. Families also experience limited support from providers and community members who have little knowledge of FASD [11, 14, 17-19]. Secondary conditions cause

many parents to worry about their children's safety and future, especially as children reach adolescence and adulthood [14-15].

Secondary conditions are also very costly to families and society. The total lifetime cost for an individual with FAS is estimated at 1.6 to 2.5 million dollars [20]. Annually, FAS costs the U.S. anywhere from 156.7 million to 8.5 billion (adjusted to 2010) dollars (adjusted median estimate = 3.25 billion; [20]). This large range is due to the different methods and assumptions in estimating cost indicators across studies. These values also likely underestimate the true costs as studies only considered individuals with the most severe form of FASD. These costs could be greatly lowered if the rates of secondary conditions were reduced.

Much work is needed to reduce the high rates of secondary conditions and the burden associated with FASD on individuals, their families, and society. The current study presents data on systems-level barriers that contribute to the development of secondary conditions in FASD. These data were gathered in the context of a qualitative investigation that sought to identify the needs and wants for a preventive intervention from the perspectives of service providers and parents of children with FASD. This is the first study to describe the relations among systems-level barriers within the context of preventing secondary conditions in this population.

## **METHODS**

### **Participants**

Participants included parents of children with FASD and providers who had professional contact with children with FASD and their families in up-state New York. Twenty-five parents were recruited through support groups, posted flyers and brochures, and family-oriented conferences. One parent was a biological mother and the remainder had adopted internationally or through the foster care system. Parents reported that their children ranged in age between 3 and 33 years old (mean = 15.62, standard deviation = 8.15). A total of 18 providers participated and included 9 pediatricians, 2 neuropsychologists, 1 therapist, 2 FASD educators, 2 educational advocates, and 2 social workers. Providers were recruited through an FASD surveillance system established in the region, local conferences, and referrals from other providers. Demographic information of participants can be found in Table 1.

### **Procedure**

This qualitative study utilized a phenomenological approach. The data presented herein are part of a larger study evaluating the wants and needs of the community for a preventive intervention for children with FASD. Participants were given the option of participating in an individual interview or a focus group. The first author conducted all interviews and focus groups. Similar questions were asked in both interview and focus group formats and covered the following topics: 1) strengths and challenges of children with FASD and their families; 2) key areas to target in an intervention; 3) ideal age range for the intervention; 4) intervention length; and 5) perceived incentives and obstacles. The study was reviewed and

approved by the Research Subjects Review Board (RSRB) at the University of Rochester and written informed consent was obtained from each participant prior to interviews. Sixteen parents elected to participate in focus groups. Two groups were held, each with 8 parents. Nine parents completed interviews (a total of 6 interviews; 3 included both parents). Eleven providers completed individual interviews and 7 providers from the same group medical practice completed a group interview.

## Data Analysis

Individual and focus group interviews lasted between 29 and 89 minutes. All interviews were audio recorded and later transcribed verbatim. Data were analyzed manually using the framework approach described by Pope, Ziebland, and Mays [21]. The research team sorted data across broad domains, and then identified themes within these domains. New domains were added to a revised model as they arose from the data. Transcribed data were then systematically coded within broad categories to identify themes. Themes were examined by various characteristics including participant type, occupation (providers), and children's age (parents). No differences were identified based on these characteristics and therefore data were collapsed together for further analyses. A revised analytic framework was subsequently developed to illustrate the relationships among the themes generated from the data. Data were then mapped onto this framework to explain the perspectives of participants (see Figure 1). The analytic framework was also presented to the parents in a second round of focus groups (3 focus groups, 21 total participants, 5-9 per group) as part of participant verification to ensure data were presented accurately.

## RESULTS

### Introduction to the Model

To prevent secondary conditions in individuals with FASD, participants indicated that FASD needs to be recognized and diagnosed early, and appropriate services need to be put in place to support the child and family. Parents and providers emphasized the many systems-level barriers that interfere with this process and contribute to secondary conditions. Systems-level barriers include delayed diagnosis, difficulty qualifying for services, limited availability of services, poor implementation of services, and difficulty maintaining services. Barriers are all related to a pervasive lack of knowledge about FASD that permeates multiple systems and the community as a whole. The five systems-level barrier subthemes and the central overarching theme of lack of knowledge of FASD will be elaborated below. For a visual illustration of the model see Figure 1. Evidence in the form of direct quotes from participants supporting each theme is provided in Table 2.

### Barrier #1: Delayed Diagnosis

A number of obstacles hinder the recognition of FASD and very commonly lead to delayed diagnosis. One such obstacle is that FASD is often not considered a possible cause of a child's difficulties or behavior. Limited or lack of knowledge of FASD may lead parents, teachers, and providers to overlook an FASD diagnosis. Another obstacle is misdiagnosis. Children with FASD are often initially diagnosed with learning disabilities, attention deficit hyperactivity disorder, or other mental health conditions. Although these diagnoses may fit

with the child's behavior, they typically do not fully capture a child's difficulties. Furthermore, many of the interventions used to treat these conditions do not work well for children with FASD because they do not match the behavioral etiology. Usually the child is not referred for an FASD evaluation until the family encounters a knowledgeable provider or parents learn about FASD through their own efforts. Unfortunately, the child may have struggled for many years with inadequate interventions and supports prior to this recognition, making behavior change more challenging. Parents and providers commented that children who received a diagnosis later were more likely to have secondary conditions.

Another major challenge in obtaining a diagnosis is the limited number of providers who are capable of diagnosing FASD. Parents often had difficulty finding a provider to conduct a diagnostic evaluation, and physicians were not always knowledgeable about where to refer families for evaluations. In the multi-city region in which the study was conducted, participants identified one provider who has expertise in diagnosing FASD and who regularly evaluates children as part of his clinical practice. A few other providers who occasionally diagnose FASD were also mentioned. Waitlists for diagnostic specialists and neuropsychologists are commonly long and can take 6 months or more for the child to be seen.

### **Barrier #2: Qualifying for Services**

Parents expressed frustration about the difficulty of obtaining appropriate services for their children. Children with FASD often do not initially qualify for services because FASD is not an established category within the developmental disabilities or educational systems. Because FASD is not classified within these systems, families often have to file appeals or find alternate ways for the child to qualify for services. Often children with lower IQ scores or other evident disabilities (e.g., severe speech delay, autism) can more easily qualify for services under other categories and generally have fewer secondary conditions.

### **Barrier #3: Availability of Services**

No services were available that targeted children with FASD within the region in which this study took place. Only one monthly support group meeting for parents is available in each of the two major cities included in this study.

Sometimes parents are searching for a particular type of service (e.g., counseling, social skills groups, respite), but are unable to find a program or provider in their community that can meet their child's needs. The availability of services is especially problematic for adults with FASD. Few services exist for adults with developmental disabilities in general, and many that do exist have long waiting lists or are a poor fit for higher-functioning young adults with FASD.

Even when children with FASD qualify for services, parents often have difficulty finding a provider who is knowledgeable about FASD. Parents described having to educate teachers and mental health providers about FASD so they could better help their children. While many providers and school personnel were receptive to learning about FASD, parents felt frustrated and discouraged that they needed to constantly educate them. Parents often

learned about providers who had some knowledge of FASD through word of mouth at support group meetings or online listserves.

For children who qualify for developmental disabilities services, few providers exist who accept Medicaid reimbursement. Participants also reported that budget cuts have resulted in fewer services available and less funding for their child to participate in recreational programs.

#### **Barrier #4: Implementation of Services**

Parents who were successful in obtaining services through the schools and community felt that services were not always implemented well. Sometimes, services were not tailored to the individual child's specific strengths and weaknesses or the function of the behavior. Participants reported that many teachers and other providers who claimed to know about FASD, did not seem to understand how FASD presents differently for each child. Other times services were not implemented as written because staffing resources were not adequate. Older children and teenagers with FASD are also sometimes resistant to accepting help because they do not want to appear different from their peers. For children who qualify for developmental disabilities services, recent budget cuts have resulted in less time and support from their Medicaid coordinator. With limited or no coordinator support, parents described feeling overwhelmed with trying to find and coordinate services for their child.

#### **Barrier #5: Maintaining Services**

Another challenge participants described is maintaining services once children receive them, especially within the context of the school system. Often times, professionals will push to remove services when an intervention or accommodation is successful and the child improves. However, children with FASD often need these supports to maintain success and begin to struggle again when they are removed. Parents reported having to fight to keep services in place and described having difficulty getting a service back once it was discontinued.

#### **Overarching Construct: Lack of Knowledge of FASD**

Every participant mentioned the need for greater knowledge and understanding of FASD and many linked this problem to the rates of secondary conditions in this population. Participants emphasized that the lack of knowledge about FASD permeates all aspects of society, including medical and mental health professionals, the education system, religious communities, the judicial system, and extended family members and friends. Parents stated that they constantly have to educate others about FASD and explain their child's behavior. Many parents described feeling stigmatized and isolated from their community by their child's behavior and the lack of understanding by others. Families also often feel frustrated by the challenges of obtaining an appropriate diagnosis and services for their children. They report feeling especially frustrated by providers who they feel should be knowledgeable about FASD, such as medical providers, mental health providers, and teachers. Very few providers who participated in this study reported having any significant coursework or formal education on FASD during their training. The majority indicated that they learned

about FASD when they began working with a client with FASD and educated themselves to try to help the individual.

## DISCUSSION

Given that prenatal alcohol exposure is the single largest preventable cause of developmental disabilities, the extent and pervasiveness of the lack of knowledge about FASD across systems was unexpected. It is a public health catastrophe that primary prevention of FASD has been so ineffective. In addition, the lack of secondary prevention programs for this population is an important public health issue. Both service providers and parents of children with FASD emphasized that overcoming systems-level barriers is a major obstacle to preventing secondary conditions in individuals with FASD. Systems-level barriers interfere with families' abilities to obtain a diagnosis and access appropriate services that meet the needs of their children. When the needs of an individual child are not recognized and adequately supported, the child is more likely to develop secondary conditions. Systems-level barriers identified in the current study include delayed diagnosis, difficulty qualifying for services, limited availability of appropriate services, poor implementation of services, and difficulty maintaining services. The pervasive lack of knowledge and understanding of FASD is a primary source of these system-level barriers and contributes to the rates of secondary conditions in this population.

Results from the current study are generally consistent with findings from previous quantitative and qualitative research. Research highlights a lack of knowledge and understanding of FASD in trainees and professionals across medical, mental health, educational, legal, and child welfare fields [11,19, 22-26]. A few brief survey studies have documented adequate basic knowledge of FASD across professions [27-28]; however, several studies suggest that while providers may have basic knowledge about FASD, they often have difficulty applying this information when implementing services [28-29].

Previous research has identified that obtaining an early diagnosis (before age 6) and receiving developmental disabilities services are two of the most important protective factors against developing secondary conditions in individuals with FASD [8-9]. However, the current investigation and several other studies demonstrate that many individuals with FASD have difficulty getting a diagnosis and do not easily qualify for developmental disabilities services [11, 19]. As mentioned above, a large nationwide study in the U.S. during 2002 and 2003 identified some similar systems barriers from participants' testimonies in town hall meetings [11]. Over 500 parents and professionals in 15 states provided testimony (limited to 5 minutes each) for the study. Data analysis focused on the number of times an issue was mentioned. Some of the most frequent complaints included a general lack of appropriate services for individuals with FASD, a scarcity of knowledgeable providers to diagnose and provide services, and difficulty qualifying for services. The more in-depth design and thematic analysis used in the current study further elaborate on these themes within the context of the prevention of secondary conditions. The fact that both studies identified some similar themes - despite different designs, research questions, geographical regions, and analytic methods - suggests the transferability of some study

findings. The similarity in themes also illustrates the great need for more effective policies and systems changes as many of the same problems exist 10 years later.

The current study is the first qualitative investigation in the U.S. to describe in detail the systems-level barriers that contribute to secondary conditions in individuals with FASD. A unique contribution of this study is describing how these systems-level barriers are related to the development of secondary conditions. The current study also identified two systems-level barriers, specifically difficulty implementing and maintaining services, which have not been previously emphasized. The recognition of these two barriers is significant, as they highlight the importance of not assuming that once an individual receives services that his or her needs are being met. Awareness of these issues is important for the prevention of secondary conditions.

A broader review of the literature reveals that systems-level barriers are also common for other developmental disabilities (e.g., [30-32]). Although many conditions could benefit from further provider education and training, greater service availability, system integration, and funding, the current study highlights some systems-level barriers that may be more salient or have unique aspects for individuals with FASD. The barriers of delayed diagnosis and qualifying for services may be more problematic for individuals with FASD. FASD is more prevalent than many other developmental disorders, but far fewer providers are adequately trained and routinely make FASD diagnoses. The lack of a reliable biomarker or “gold standard” psychological assessment for FASD coupled with minimal training on the condition in medical education likely contribute to this problem. Obtaining adequate services is a challenge for many individuals with developmental disabilities, but may be especially difficult for individuals with FASD as they do not easily fit within the qualification categories utilized in most service systems (i.e., special education, developmental disabilities). Future research evaluating the similarities and differences in systems-level barriers facing individuals with various conditions may improve outcomes and service delivery for all developmental disabilities.

### Limitations

While the study sought to include a wide range of perspectives from parents of children with FASD and service providers representing multiple disciplines, findings from the current study may not reflect the views of all families and providers. The families included in the current study were predominately foster/adoptive families who at some point recognized their child had FASD and actively sought out supports. Although one biological mother participated in this study, the inclusion of additional biological parents may have resulted in different or additional findings. The proportion of biological families represented in this study and others (e.g., 11, 16) suggests that alternate recruitment efforts may be needed to obtain this important perspective. The racial/ethnic backgrounds of parents in the current study reflect a somewhat greater proportion of Caucasian individuals than is representative of the population in the region. However, the rate is consistent with rates of service seeking parents raising children with FASD in the study area and rates reported in previous studies. In terms of providers, we were unsuccessful in recruiting classroom teachers who had experience working with children with FASD and were able to participate in this study.



Although a couple of the providers in this study had been classroom teachers earlier in their careers, they had not taught children identified with FASD and likely have different perspectives in their current positions than many teachers actively working in the classroom. Future research with classroom teachers may provide additional insights into this important research question.

### **Implications and Recommendations**

Secondary conditions are a large contributor to the lifetime cost burden for an individual with FASD [20]. Preventing these conditions could result in a significant savings to the public and reduce the suffering of the individual and his or her family. The current study identified that broad systems changes are needed at the public health level to support the prevention of secondary conditions in this population. See Table 3 for a summary of recommendations.

First and foremost, the general public needs to be more aware of FASD. It is unacceptable that a condition that affects as much as 2 to 5 percent of the population [3] and leads to overwhelming costs to the individual and society [20] is so poorly recognized and understood. Many people have the basic knowledge that heavy drinking during pregnancy could be harmful to the fetus, but have little knowledge of how it affects children and adults during the lifespan or how to support individuals with FASD. Public health campaigns are greatly needed to address this lack of knowledge. Providers in all systems serving the community need comprehensive training on FASD and how to work with this population to effectively meet their needs and the needs of their families. Curricula have been developed for providers in various fields [33], but policies requiring or providing incentives to incorporate these curricula in training programs or continuing education are needed.

In addition to improving knowledge and understanding of FASD, additional public health policies are needed to address systems-level barriers. Medical systems need to leverage support for more multidisciplinary diagnostic clinics to reduce the challenges of obtaining a diagnosis. Screening high-risk individuals for FASD, such as children in the child welfare, criminal justice, and special education systems, would increase the number of individuals who are recognized and diagnosed. Several studies documenting higher rates of FASD in these systems have demonstrated screening can be effectively implemented [34-36]. Once diagnosed, families need to be able to qualify for and access appropriate services for their children. Currently FASD is not included within the classification systems that are used by the developmental disabilities and educational systems. These classification systems should be revised to include FASD as a recognized disability or alternate ways for more children with FASD to receive services need to be identified. Even if children with FASD can qualify under different categories within these classification systems, providers need to understand how individuals' behavior is affected by their neuropsychological strengths and weaknesses relating to their FASD diagnosis. Without this understanding, interventions are unlikely to adequately support the individual. The availability of appropriate services also needs to be drastically increased. Empirically supported interventions designed for individuals with FASD are increasingly being published in the research literature [37-38]. Efforts are being made to disseminate these interventions, but much larger public health campaigns are

needed to promote these interventions within communities where they are accessible to families. Greater knowledge and better understanding of FASD will aid providers in implementing services more effectively for this population and help them recognize the need to maintain services for many individuals. An earlier diagnosis coupled with the implementation and maintenance of appropriate services would greatly reduce the level of secondary conditions in this population. All of these changes would improve outcomes for individuals with FASD and reduce the burden on them, their families, and society as a whole.

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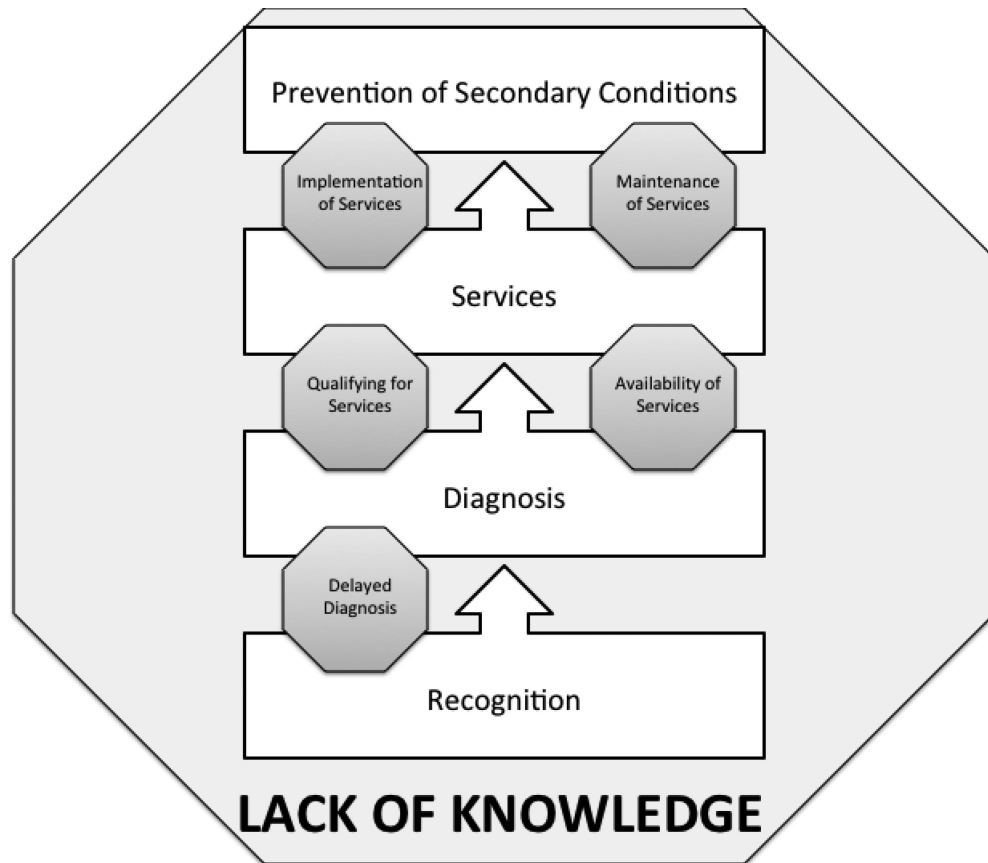
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**Figure 1. Visual model of systems-level barriers for individuals with FASD**  
 Five systems-level barriers interfere with the prevention of secondary conditions in individuals with FASD. These barriers include delayed diagnosis, qualifying for services, availability of services, implementation of services, and maintenance of services. All of these barriers are related to a pervasive lack of knowledge of FASD across systems.

**Table 1**

## Participant demographic characteristics

	Parents (n = 25)	Providers (n = 18)
Sex [n (%)]		
Female	16 (64.0%)	14 (77.8%)
Male	9 (36.0%)	4 (22.2%)
Age [Mean (standard deviation)]	53.56 (8.27)	48.83 (11.96)
Age Range	30–65	28–64
Race/Ethnicity <sup>a</sup> [n (%)]		
White	22 (88.0%)	15 (83.3%)
African American / Black	3 (12.0%)	1 (5.6%)
Asian	0 (0.0%)	1 (5.6%)
Level of Education [n (%)]		
High school diploma / GED	1 (4.0%)	0 (0.0%)
Some college / Associates	14 (56.0%)	0 (0.0%)
Bachelors degree	7 (28.0%)	3 (16.7%)
Masters degree	3 (12%)	4 (22.2%)
Doctoral degree	0 (0.0%)	11 (61.1%)

<sup>a</sup>Participants did not endorse any other racial or ethnic categories. One provider declined to provide racial/ethnic data.

**Table 2**

## Supporting evidence of systems-level barriers for individuals with FASD

<b>Participant [ID#]</b>	<b>Direct Quotation</b>
<b>Barrier #1: Delayed Diagnosis</b>	
Foster/Adoptive Father of 3 and 5 year-old sons [C20]	A lot of them don't even know how to recognize certain, what this kid has, what's wrong with this kid, or what's going on. They don't see it. And then they get frustrated. Now they gonna label the kid as a "bad child" every chance they get, they gonna be kicking the child out of school. You know. That's not helping the child.
Adoptive Mother of 28 year-old son [C24]	Recognizing it early.. .The whole child was never addressed with him.. .They had him ADD, they had him fine motor. They never really could identify anything, but now it's [FASD] out there.
Adoptive Mother of 33 year-old daughter [C23]	I would say I accidentally discovered she had fetal alcohol syndrome disorders by watching a movie - <i>The Broken Cord</i> ... And I searched out the doctor to find out if she did have it, and because, it just explained everything that I had gone through. We adopted her at three years of age, so we had gone, what 17-18 years, with just so much gambit of things, and not really understanding what she could do, what she couldn't do, it was so confusing.
Adoptive Mother of 13 year-old son [C15]	There's not that many [FASD experts] around, and even pediatricians don't have the knowledge to send you to where you need to go [to get a diagnosis].
FASD Educator and Advocate [P05]	A lot of the young people that I see now that I know had an early diagnosis and families that were really well educated and worked, you know, at this for years, they're the ones who seem to be doing very well. Where as there are others that I know they only got the diagnosis when they were twelve or thirteen and at eighteen or nineteen some of them are already having trouble with the law.. .It's just like there just was too much going on all those years, and people not understanding.
<b>Barrier #2: Qualifying for Services</b>	
Adoptive Father of 28 year-old son [C25]	You need to have FASD classified and recognized as a categorical developmental disability so it can get status, so that people can become eligible for Medicaid funded services. And the same level as people with autism, or learning disabilities, or any developmental disabilities to automatically get them qualified for Medicaid.
Foster/Adoptive Father of 20 year-old daughter [C14]	[biggest challenges] getting into the system where you can be qualified to receive like respite care, or other services like being able to take horseback riding lessons.
Educational Advocate [P03]	I know through us, they gotta be OPwDD eligible, and I know that one of the cases I did they had to appeal like 3 times. Because we have a great social group here but the child's gotta be eligible for our services... They have to fit in one of the 13 under IDEA to get services [in schools]. It's getting them to fit in one those categories to try to qualify them for services. So there is a challenge there too.
Foster/Adoptive Mother of 20 year-old daughter [C13]	I think it's harder too, when your child has an average IQ. Our daughter's was lower, and so it was easier to get the services.
FASD Educator and Advocate [P05]	You know more severely, cognitively - surprisingly those are the children who are going to get services, and the parents are going to get more support because it's a more visible disability.
<b>Barrier #3: Availability of Appropriate Services</b>	
Foster/Adoptive Mother of 7 year-old daughter [C06]	[What would be helpful?] A ready list of professionals or even places that we can seek help. I mean I had to do my own research, trying to find something somewhere because nobody seemed to know anything that would help.
Foster/Adoptive Mother of 5 year-old daughter [C07]	The counselor is important. Our struggle is finding a counselor who knows enough about fetal alcohol spectrum disorder to be able to help the child.
Neuropsychologist [P18]	I think there's one district maybe out of 15 that really gets it...a lot of advocacy required by me, and I'm happy to do it, but it just feels like we're reinventing the wheel in every district here.
Adoptive Father of 11 year-old daughter [C05]	There's so many people that need assistance and not so many people that are doing it. I mean they have the funding but you have to find somebody actually to do it for you. And it's hard to find people that are willing to, who are qualified.
Social Worker [P07]	One of the issues with mental health services especially has been Medicaid. You know they only have so many choices of places that they can go when their child is covered by Medicaid. So that's a huge issue.

Participant [ID#]	Direct Quotation
Educational Advocate [P03]	The biggest challenge that if they actually need a day program, there's going to be wait lists due to the budget constraints in New York State. I don't know how many new programs are going to be developing through service agencies to meet the needs of all the kids transitioning out.
<b>Barrier #4: Implementation of Services</b>	
Educational Advocate [P04]	I would say the lack of information, and then the understanding on how to implement the strategies on how to work with the student. If you think the student is doing it on purpose, or you think they're just willfully - you know, the way you're going to react to it.
Adoptive Mother of 18 year-old son [C10]	[Teachers] can say "Oh yeah, we've had kids with FAS before," but you haven't had my son. You haven't had her daughter, you haven't had your daughter, or your son. Every kid is different and I don't think they understand. I think that's the biggest drawback. They expect more out of them, and don't understand when they don't.
Adoptive Mother of 14 year-old son [C08]	And it's very hard because they don't know how to help in these groups. Even though there are groups that our kids can go to, once you get services, it's very difficult because they're not like the other kids with disabilities. They're not like them at all.
Adoptive Father of twin 15 year-old sons [C03]	When they take a test they're supposed to be taken out. One of the teachers told me if they don't use that privilege they'll lose it. And that came up in a meeting and I found out that she was wrong. It's not use it or lose it - it's there forever.
Foster/Adoptive Mother of 20 year-old daughter [C13]	They've got so many budget cuts. But they [Medicaid coordinators] just don't have the time to spend like they used to. Ours used to spend a lot more time with us.
Adoptive Father of 12 year-old son [C12]	I think that's where we struggle with. This is so fragmented that I gotta go here for this, gotta go here for this, gotta go here for this. And if I didn't know this was over here, if I heard about it, I'd go over here. But some days, you really have to tie all the pieces together.
<b>Barrier #5: Maintaining Services</b>	
Adoptive Father of 11 year-old daughter [C05]	We've tried to educate them on the subject, and they still to this day, when they see her, they think she's advancing, they want to pull things back. "What does she need an aide for? Why does she need to have the study notes sent home with her?"... After a while they seem to think that we're crazy, that we're over protective...we want to be proactive...The reason that she's been able to excel to where she is now, is because of all that's been in place since she was a baby. If not for that we don't know where she would be.
FASD Educator and Advocate [P05]	One of the things that I see a lot of in the schools is that they're always trying to, you know, push the child to the next level of independence, which is not in itself a bad thing, but in many cases what they don't realize is that some of the supports and structures that were in place, is why the child is doing better, and once you take those away it's like pulling one of the legs out of that proverbial three legged stool, where all-you know, its holding it up, but when you pull it away, it all falls apart.
<b>Overarching Construct: Lack of Knowledge of FASD</b>	
Adoptive Mother of 33 year-old daughter [C23]	Society needs to be more aware of this disability. There's nothing now. No conversation for fetal alcohol syndrome disorder. There are no services, no helps. There's nothing for adults, basically.
Adoptive Father of 12 year-old son [C12]	I think that's across the board too, you know your pediatrician, your doctor... we have to educate everyone we come in contact with what is FAS. How does this exhibit. I mean it can be from a Sunday school teacher, to a coach, to anybody you know. Like I said, pediatricians, doctors, who should know, don't.
Biological Mother of 9 year-old daughter [C01]	Well when we go out into the community it is hard with church and stuff. We've gone through a couple of different churches because of the behaviors. People just don't understand and they don't have the compassion.
Foster/Adoptive Mother of 7 year-old daughter [C06]	I think the biggest challenge is that people don't understand why they do certain things, what their challenges are. Most of the time they appear normal and then something sets them off and you've got a wild child.
Adoptive Mother of 14 year-old son [C08]	I don't think too many people are that well versed in FAS. You know administrators, even. I don't think Special Ed. - you know CSE chair people - I don't even think they're that well educated about FAS.
Pediatrician [P02]	Too often is that teachers don't know about Fetal Alcohol Syndrome. They don't know about it, they have not had training about it. The school system, the school environment in which they work doesn't allow them to provide the kind of time that it takes for a child. teachers have an especial challenge, the disability, it doesn't always appear to be a disability. You know sort of the data that teachers typically rely, often times are in the normal range, and so it can lead to substantial challenges as teachers.



Participant [ID#]	Direct Quotation
FASD Educator and Advocate [P05]	I've tried to educate a lot of the providers who serve as advocates in the school, so that hopefully they have information. Really just try to get it almost through the system, but it's really a challenge because I find that no matter how many times I've been there, there's always somebody with a question that makes it very clear that they don't understand FASD at all.
Therapist [P10]	I think there needs to be more knowledge, and then a grassroots surge of people who are putting pressure for more services and insurance companies, and making this more widely known. It's got to be diagnosed more often. There has to be more study.

**Table 3**

Summary of recommendations to address systems-level barriers in the prevention of secondary conditions in FASD.

<p><b>Overarching Construct: Lack of Knowledge of FASD</b></p> <ul style="list-style-type: none"> <li>➤ Increase awareness of FASD in the general public           <ul style="list-style-type: none"> <li>○ Public health multimedia campaigns</li> <li>○ Inclusion of FASD topics in secondary education</li> </ul> </li> <li>➤ Incorporate training and requirements for knowledge and skills in FASD prevention, diagnosis, and service provision across professions (e.g., education, medical, nursing, mental health, judicial, speech/OT/PT)           <ul style="list-style-type: none"> <li>○ Training programs</li> <li>○ Licensing and Accrediting Boards</li> <li>○ Continuing education</li> </ul> </li> </ul>
<p><b>Barrier #1: Delayed Diagnosis</b></p> <ul style="list-style-type: none"> <li>➤ Increase the number of multidisciplinary diagnostic clinics for FASD</li> <li>➤ Screen individuals at high risk for FASD (e.g., individuals within child welfare, judicial, and special education systems)</li> <li>➤ Increase the number of providers who are capable of diagnosing FASD</li> </ul>
<p><b>Barrier #2: Qualifying for Services</b></p> <ul style="list-style-type: none"> <li>➤ Revise service classification systems (e.g., special education, developmental disabilities) to include FASD as a recognized disability or establish alternate ways for children with FASD to qualify for needed services</li> <li>➤ Educate providers in identifying how an individual's neuropsychological profile relating to their FASD diagnosis impact their behavior</li> </ul>
<p><b>Barrier #3: Availability of Services</b></p> <ul style="list-style-type: none"> <li>➤ Increase the number of providers who are able to provide appropriate services to individuals with FASD</li> <li>➤ Increase the dissemination of interventions for individuals with FASD and their families</li> <li>➤ Integrate interventions into existing systems of care</li> <li>➤ Promote the availability of FASD-related services in the community and coordinate across systems so families can more easily access them</li> <li>➤ Increase funding for program evaluation and research studies on the efficacy/effectiveness of interventions for individuals with FASD and their families           <ul style="list-style-type: none"> <li>○ Existing interventions developed for other populations or used broadly in the community</li> <li>○ Interventions developed specifically for individuals with FASD</li> </ul> </li> </ul>
<p><b>Barrier #4: Implementation of Services</b></p> <ul style="list-style-type: none"> <li>➤ Train providers in how to tailor services to the needs of individuals with FASD</li> <li>➤ Provide sufficient resources and supports to implement the service required</li> </ul>
<p><b>Barrier #5: Maintenance of Services</b></p> <ul style="list-style-type: none"> <li>➤ Educate providers and systems about the need of continued accommodations for many individuals with FASD to maintain success</li> </ul>