A QUALITATIVE ASSESSMENT OF PROGRAM CHARACTERISTICS FOR PREVENTING SECONDARY CONDITIONS IN INDIVIDUALS WITH FETAL ALCOHOL SPECTRUM DISORDERS

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ABSTRACT

Background
Fetal alcohol spectrum disorders (FASD) are a major public health problem that affects 2 to 5 percent of the population. Individuals with FASD are at high risk for secondary conditions, such as mental health problems, school disruptions, and trouble with the law. Evidence-based intervention programs are needed to prevent and treat secondary conditions in this population.

Objectives
The purpose of this study was to identify intervention program characteristics for preventing secondary conditions in individuals with FASD from the perspectives of parents and service providers.

Methods
This qualitative study utilized a phenomenological approach to identify program characteristics for preventing secondary conditions. Twenty-five parents of children (ages 3 to 33) with FASD and 18 service providers participated in focus groups or individual interviews. Data was systematically analyzed using a framework approach. Themes did not differ by participant type.

Results
Participants emphasized five primary characteristics of intervention programs for individuals with FASD. Programs need to 1) be available to individuals across the lifespan, 2) have a prevention focus, 3) be individualized, 4) be comprehensive, and 5) be coordinated across systems and developmental stages. Participants discussed a variety of specific intervention strategies for each developmental stage and setting.

Conclusions
Program characteristics identified in this study are consistent with a positive behavior support framework. This framework is discussed in the context of research on existing interventions for individuals with FASD, and recommendations for future intervention development and evaluation are highlighted.

Key Words: *Fetal alcohol spectrum disorders; fetal alcohol syndrome; secondary conditions; prevention; intervention; qualitative methods*

Fetal alcohol spectrum disorders (FASD) are a major public health problem. In the United States and other western countries, the prevalence of FASD is estimated at 2 to 5 percent of the population.[1] Individuals with FASD have life-long cognitive and behavioral disabilities as a result of prenatal exposure to alcohol.[2] Due to multiple systems-level barriers[3], many individuals with FASD are not appropriately diagnosed and have difficulty obtaining services to support their primary cognitive and behavioral disabilities. Parents and other adults can easily misinterpret the behaviors of individuals with FASD. As a result, secondary conditions (also known as "secondary disabilities" in seminal research in the field) often develop as the individual with FASD attempts to cope with the stress and frustration of not feeling understood or accepted by others.[4-6] Secondary conditions occur at high rates in individuals with FASD and include mental health problems (lifetime prevalence 95%), school disruptions (i.e., suspended, expelled, dropped out; 61%), trouble with the law (60%), confinement (e.g., jail, inpatient psychiatric treatment; 50%), inappropriate sexual behaviors (49%), and substance use problems (35%).[5-6] The onset of many secondary conditions dramatically increases during the transition from childhood to adolescence. The most consistent protective factors against these secondary conditions in this population include an early diagnosis before age 6, receipt of developmental disabilities services, a diagnosis of fetal alcohol syndrome (vs. other FASD), a stable and nurturing home environment, and not being the victim of violence or maltreatment.[5-6]

Secondary conditions place a heavy emotional and financial burden on individuals with FASD, their families, and society. By definition, secondary conditions can be prevented if an individual's primary disabilities are well supported. However, there is limited research on strategies and intervention approaches that are effective in preventing secondary conditions in this population. A composite case vignette is provided below to illustrate common experiences faced by individuals with FASD and their families.

Composite Vignette

Marie was removed from her biological mother's care at the age of 18 months as a result of neglect, substance use, and domestic violence in the home. Marie lived in two different foster homes and was formally adopted at age 4 after her mother's parental rights were terminated. Marie was an engaging child who enjoyed talking with adults and playing outside. She had a lot of energy and often got in trouble at school for not listening and disrupting others in the classroom. Due to her high activity level and problems with impulse control, other children often excluded her during playtime. As she progressed through school, she began having greater difficulty with reading and math. After receiving a diagnosis of attention deficit hyperactivity disorder (ADHD) in the 2nd grade, her parents requested an evaluation for special education services at school. The results of the evaluation found Marie's IQ was 83 and her reading and math scores were well below average for her grade. As a result, she qualified for consultant teacher services in math and reading and was provided accommodations for preferential seating in the classroom.

Marie continued to struggle throughout elementary and middle school. Her parents grew increasingly concerned about her behavior and learning problems. Homework was becoming a struggle in the evenings and meltdowns were common. Her parents also noticed she was becoming more withdrawn and were concerned about her self-esteem. They took her to the child psychiatry clinic where she was diagnosed with a mood disorder and her medications were adjusted. Marie and her parents also started seeing a therapist who worked with her parents on strategies to manage her behavior at home. Her parents tried implementing time out and token systems as recommended, but found they didn't work with Marie. She just didn't seem to learn from consequences and it seemed like it didn't matter what her parents did. Marie's parents were starting to feel discouraged and hopeless. Her mother spent a lot of time on the internet in the evenings trying to understand what was wrong with Marie and how to help her. One evening she stumbled upon a website about FASD and thought the description sounded a lot like Marie. After some searching, she discovered that there was a diagnostic clinic an hour away. After a 6-month wait, Marie was seen in the diagnostic clinic and was diagnosed with alcohol-related neurodevelopmental disorder, a diagnostic category of FASD. Marie's mother joined a local support group and tried to find services to help Marie. She was surprised to learn there were no services for FASD and was discouraged hearing stories from other parents whose children were struggling as adolescents and adults. Marie's parents took her to see multiple psychiatrists and behavioral specialists over the next few years, with only modest results. They found many of the professionals and teachers had little knowledge about FASD and didn't know how to best help her. Her parents tried their best to figure out strategies by trial and error. They noticed that her success in school really depended on the teacher and how receptive the teacher was to learning about FASD and trying different strategies to support her. Choir also seemed to be a great outlet for Marie at school and she met a couple of girls who accepted her in the group.

In high school, Marie began taking vocational classes and participated in job training programs. The relationship between Marie and her parents became increasingly strained as she was often disrespectful and did not follow house rules. She was starting to hang around with kids at school who they felt were negative peer influences and they were concerned about delinquency and substance use. In 11th grade, Marie was caught stealing items from school and was suspended. Her parents knew there were no adult services for people with FASD and they were worried about what she would do after high school and where she would live. They feared Marie was on a path to many of the negative outcomes they had heard from families in the support group.

The Current Study

The goal of the current study was to identify characteristics of intervention programs that might be effective in preventing secondary conditions in individuals with FASD. Given the nascent research literature on preventive interventions in FASD, this study sought to draw upon the lived experiences of parents of individuals with FASD and service providers. Parents and service providers have important and unique perspectives on the strengths and challenges of individuals with FASD and the types of services and supports that might be most effective in preventing secondary conditions. Decisions about intervention programming for individuals with FASD almost always involve their parents or legal guardians. If programs are not consistent with parents' beliefs and values or do not accommodate families' busy lives, individuals will not or cannot participate. In addition, intervention programs need to be acceptable to service providers in the community, who ultimately need to adopt the program and implement it with fidelity. Thus, understanding these perspectives is imperative for designing and successfully disseminating interventions that meet the needs of individuals with FASD in the community. Findings from this study will have important implications for the development of preventive interventions for individuals with FASD and their families.

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.

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[a] [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%)

[a]Participants did not endorse any other racial or ethnic categories. One provider declined to provide racial/ethnic data.

Procedure

This qualitative study utilized a phenomenological approach. 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 questioning routes were used 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.

These topics were selected to elicit perspectives on ideal program characteristics to prevent secondary conditions and to assess the factors that affect program relevance for the local community. The study was approved by the University of Rochester Research Subjects Review Board and each participant provided written informed consent 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.

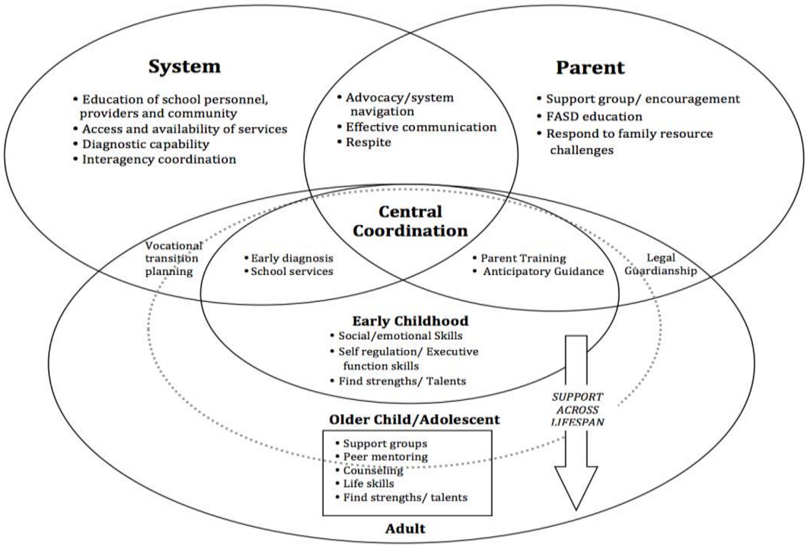
Data Analysis

Individual and focus group interviews lasted between 29 and 89 minutes. All interviews were audio recorded and later transcribed verbatim. Data were analyzed using the framework approach described by Pope, Ziebland, and Mays.7 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 majority of parents in the sample 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

Parents and service providers identified five ideal program characteristics for the prevention of secondary conditions in individuals with FASD. Based on their experiences, participants indicated that programs need to 1) be available to individuals across the lifespan, 2) have a prevention focus, 3) be individualized, 4) be comprehensive, and 5) be coordinated across systems and developmental stages. The details of these recurrent themes are expanded upon below. Evidence in the form of direct quotes from participants supporting each theme is provided in the tables of associated sections. Participants also discussed a wide variety of specific intervention strategies that could be used in programs incorporating these characteristics depending on the age and needs of the individual. For a visual illustration of the model see Figure 1.

FIG. 1 Visual model of identified program characteristics and specific intervention strategies for the prevention of secondary conditions in individuals with fetal alcohol spectrum disorders (FASD). Preventive interventions for this population need to be available across the lifespan, focus on preventive strategies, be individualized, comprehensively address the needs of the individual and family, and be integrated and coordinated across components. Specific intervention strategies are depicted according to the person(s) or settings involved (e.g., parent, individual with FASD, school, other providers) and developmental stage of the individual with FASD.



Lifespan

Participants emphasized that FASD is a life-long disability and therefore services are needed across the lifespan (see Table 2). Preschool to early school age was the most frequently mentioned developmental period for initiating preventive interventions with children with FASD and their families. However, others also suggested working with the parents as soon as possible (i.e., ideally at birth or at the time of foster placement/adoption) once the diagnosis is suspected. While early intervention is critical in prevention, the need for continued services was also emphasized throughout childhood and into adolescence and adulthood.

TABLE 2 Supporting quotes for interventions across the lifespan in individuals with FASD

Participant [ID#]	Direct Quotation
Adoptive Mother of 18 year-old son [C10]	As I said from cradle to grave. … Because the disability doesn't go away, it just changes, the manifestation changes. There's different challenges with every age.
Adoptive Father of 21 and 22 year-old daughters [C18]	Well it should start earlier, but I think those services should continue and should be enhanced or modified for teenagers.
Adoptive Mother of 14 year-old daughter [C21]	I think it has to be life-long.
Adoptive Father of 28 year-old son [C25]	They don't get cured. So it's not like you can have the interventions up until they're 21 and then think that they can go on their merry way and be like everybody else.
Physician [P02]	Well I think that intervention, in principle in FASD is an intervention throughout the lifespan .... And it probably looks different at different developmental stages. … For example, early on it's parents and helping them sort of navigate the various systems and those kinds of things. Helping them become better advocates, and then for older people, the whole matter of supervised living of varying degrees, again depending on need.
FASD Educator and Advocate [P05]	Well, ideally, I think it should be in place so that it can continue as the young person grows and matures … Services for many individuals with FASD need to really continue throughout their entire life. … If they're going to continue to be successful, they still are going to need some support.
Neuropsychologist and Therapist [P18]	It's kind of a lifelong disability, so I, I feel like it's really important to think in terms of the whole entire life span, you know thinking like supervised, kind of residential situations and the transition from education to vocation and how you set things up so someone can be successful. The mental health piece, cause, so often, you know as you're getting older you're seeing different secondary problems.

The types of beneficial intervention strategies recommended by participants varied by developmental level. For example, social functioning was often highlighted as a major challenge for individuals with FASD across the lifespan. For younger children, participants suggested social skills groups and parent facilitated play dates as possible strategies to target this domain. For adolescents, peer mentoring and support groups were recommended given the importance of peer influences during this developmental stage. Other intervention strategies suggested for younger children include instruction in self-regulation skills and parent training. Family therapy was viewed as beneficial for older children and adolescents with FASD.

Unfortunately, there are very few services available for individuals with FASD after they finish school. The transition to adulthood is fraught with multiple developmental challenges including securing appropriate housing, selecting a vocation, managing personal finances, and establishing new friendships and romantic relationships. Many young adults with FASD are ill equipped to navigate these challenges without significant supports. Recommended services for adults with FASD focused on life skills development and vocational services. Support groups and counseling were also mentioned during focus groups and interviews, to promote positive adjustment and mental health.

Proactive / Prevention Focused

Participants reiterated the importance of taking a proactive or preventive approach, when possible, to improve outcomes for individuals with FASD and their families (see Table 3). Identifying appropriate supports and putting them into place before a child begins to struggle is likely to lead to more positive outcomes, especially during key developmental transitions. Examples of such supports that were suggested include educating teachers or residential staff about FASD, establishing appropriate expectations, creating behavior support plans that focus on antecedent strategies, and establishing legal guardianship before the child turns 18. Several parents resonated with the idea of having a “toolbox” of strategies they could use as different situations arose.

Anticipatory guidance, such as providing parents with information on what they might expect at different ages or when to consider different types of services (e.g., legal guardianship, vocational planning), was viewed as especially helpful. Many people highlighted the benefits of parent-to-parent support, either through formal support groups or individual contacts, as a good mechanism to obtain this guidance. Parents who have older children are often valued by support group members for their experience and knowledge about different strategies that worked and didn’t work for their child, especially as they relate to navigating various service systems.

Individualized

Although several areas of weakness were consistently mentioned during focus groups and interviews, (i.e., social functioning, self-regulation, school/employment), participants emphasized the importance of considering individual variability when intervening with people with FASD (see Table 4). The needs of an individual with FASD can vary widely based on pattern and dose of prenatal alcohol exposure, maternal factors (e.g., genetics, nutrition, age), post-natal environment, and the presence of co-morbid problems. Participants recommended assessing the strengths and weaknesses of each individual with FASD and their family and then individualizing interventions to capitalize on the strengths and support areas of weaknesses for the young person.

Although services can be tailored to an individual’s personal strengths and weaknesses in a group format, services delivered in an individual format were viewed as being most beneficial when teaching someone with FASD specific skills or providing counseling. However, all participants viewed the benefits of group services and activities for promoting social skills, positive self-esteem, and a sense of belonging. Combining both individual and group interventions was a common recommendation.

TABLE 3 Supporting quotes for a proactive or preventive approach in interventions with individuals with FASD.

Participant [ID#]	Direct Quotation
Foster/Adoptive Mother of 7 year-old daughter [C06]	But be prepared for each level, each age maybe. From the beginning I think to get the support down – now I am able to help other parents who are just finding out. You know if I come across somebody - like you can go here, here, or here to get help. I think every age group is going to need something different.
Foster/Adoptive Father of 20 year-old daughter [C14]	Yeah I would say that you need a manual about that thick. You need to give it to a parent and say here read this! Yeah there'll be parts in there about how to apply for services and how to deal with teachers, and how to deal with physicians who don't know what they're doing. It's something that we all kind of gleamed a little at a time, from just our own life's experience. But if someone had something like all of our learnings put into a book, or a software, or whatever, you could just say, "oh okay, I'm having trouble with school." And then be able to go off in the direction of how do you deal with school, if you're a parent of this. And, school should have a thing "okay I've had a kid in my school that's got FAS, how do I get a parent to be aware of what they need to do," or "How do we get our counselors to be able to look at this child." So that the same manual could be used by any number of different people, depending on what their specialty is.
Foster/Adoptive Mother of 5 year-old daughter [C07]	You were talking about guardianship and stuff, and I'm like "Do I need to be taking notes at what age I need to start that at?" You know, so that you know what to expect. Okay this year, these are the goals that I'm going to have to reach, I need to do this. You know, if someone checks in on a regular basis, but something more in depth, and you could know exactly what you should be doing, or might be helping that year.
Adoptive Father of 12 year-old son [C12]	Without that parent support group, and even being able to talk to people, you know "Oh yeah, my kid does that too" or … especially you guys with the view of older kids, you know, of what to expect … And kind of being able to see ahead a little bit … if we didn't have the support group, I don't know really if we'd even be thinking that way. At least from my personal standpoint. You know I'd be focused on what's going on today, versus, you know where are we gonna be five, ten years from now.
Foster/Adoptive Mother of 32 and 33 year old daughters [C23]	I wish I had known in advance what I was going to be doing, instead of stumbling into it and not being ready for what was going on. Catching me off guard surprising me, I didn't like that. … I think that part of the problem is as a parent you have tunnel vision because you're just going with them through it. You don't know what's next, and if somebody's not telling you, you're not even thinking about what's going to be down the road.
FASD Educator and Advocate [P01]	Her child with FAS - I think she's 4 or 5. So she came proactively, "my child - you know, I'm already seeing this. I think this is what's going on." We gave her [a physician's] information, …we connected her with the Advocacy Center. They went with her proactively - this is for kindergarten to put things in place already. Because she just suspected that this was not going to be a successful time for her daughter integrating her … This parent has done so much work, to put all this stuff in place.
Neuropsychologist [P06]	There's going to be a number of issues that are going to come up … So smoothing transitions so that they're not abrupt and occur more easily. Seeing that they're coming and addressing them ahead of time. Plan for behavioral problems that arise, probably in the home and school.

TABLE 4 Supporting quotes for individualized interventions for individuals with FASD.

Participant [ID#]	**Direct Quotation**
Foster/Adoptive Mother of 32 and 33 year old daughters [C23]	Each child is different and each child does have a gift. Find out what that is, what they're good at, and try to capitalize on that.
Adoptive Father of two 15 year-old sons [C03]	So slowly, deliberate, and individualized. But when it comes to a social activity, the more the merrier.
Neuropsychologist [P06]	I think that it would be important to individualize, and really maybe have a wide array of things that could be done. Avoid having too much structure that everybody gets, because there's going to be such a wide range.
Social Worker [P07]	I think in general, most people deal best with having an individual and group experience. Because they have the one on one, that's more individualized to them, and then to be in a group setting where they can see there are other people here, … You know peer messages are always the strongest message. Especially for kids.

TABLE 5 Supporting quotes for comprehensive interventions for individuals with FASD.

Participant [ID#]	**Direct Quotation**
Foster/Adoptive Mother of 5 year-old daughter [C07]	I think the holistic approach. I think you can't just fix one piece of the puzzle and the whole puzzle will be fixed. You have to intervene on all levels. You'd have to intervene with the child, with the family, and also the school and the social group around it. Because I don't think there's anyway to fix it without looking at the whole picture.
Physician [P02]	Clearly work that isn't done by one professional. … I would be thinking about parental intervention early on in terms of that whole matter of "consistence, gentle, guidance." I think working with teachers, to help them understand disability that's not associated with gross physical anomalies. And certainly the young people again in terms of iterating and re-iterating some of the general societal values that are important.
FASD Educator and Advocate [P01]	Certainly the parents have to be apart of that. If you're intervening on the child, you've got to bring in the parents to be active partners in being able to take home the intervention and be able to implement some of that or at least repeat some of it at home. And once they connect with school, you could integrate.
Educational Advocate [P03]	I think the more, the better, to be honest with you. So if it could be done at both places [school and community] and done well that would be great. But I think sometimes if its just done at school, its isolated there. You know, so if we can do something out in the community - I really think you need both pieces though.

TABLE 6 Supporting quotes for coordinated interventions for individuals with FASD**.**

Participant [ID#]	Direct Quotation
Biological Mother of 9 year-old daughter [C01]	Well maybe they should have somebody there you know when it comes down to that age - aging out [of early intervention services] - that there is somebody that takes you to the next step.
Adoptive Mother of 11 year-old daughter [C04]	Ideally it would be someone coming into the house to actually touch base with us, and touch base with [child's name] and see how things are going, and spend some time with [child's name] to see if [child's name] would open up more with that person than she would open up with Mom and Dad. But a consistent person, not a different person every time. Nobody wants to start from day one again.
Adoptive Father of 12 year-old son [C12]	Somebody to really be a partner with the parent, helping them, hold their hand through all this, to really kind of connect all the dots. I would see would be the biggest value.
Foster/Adoptive Father of 20 year-old daughter [C14]	And that one agency kind of had all the answers for everything we needed to do, for our daughter, right at that age … So just having a person that knows about everything you need to know at various stages at their life is very, very helpful.
Foster/Adoptive Mother of 3 and 8 year-old sons [C19]	If you had a central place, like a mental health place, we wouldn't call it, mental health- but a place where they can go to. They [the children] would be able to have fun there, enjoyment there, not just pointing and label him there. … Support groups would be there. You would have doctors on hand, on call … but that would be a good place to have a center that we could be able to go to, and get all the information we want.
Adoptive Mother of 14 year-old daughter [C21]	I think it would be nice if there was like a central advocacy person. You could call, and say you know I have this problem, this problem, and this problem. Where do I go?
Neuropsychologist [P06]	Yeah, I mean I think the more that you could tie it together for people between home, school, services directly to the child, organized activities. … I think the more you can tie it together for people, and have all of these options available, the more you're going to … keep these people on the same page.
Social Worker [P07]	I think it would be great to have someone available to them that they can process things with at any time. … But, to call and say, "you know here's what's happening. Here's how I feel, and here's what I want to do." And to have somebody kind of coach them through, "yeah that sounds good," or "let's think about this a little bit more," and to help them figure out who else do I need to address this with, besides the child, because there might be, you know, something at school - something else that can be addressed.
Neuropsychologist and Therapist [P18]	Some cities are fortunate to have a real cluster of people who work all within the same walls who can provide that, but most places don't have that. I mean coordinated - you know, understanding of all complexity, all the different systems. There's school issues, there's mental health, psychiatric

Holistic / Comprehensive

Given the complex needs of many individuals with FASD, it is not surprising that participants stressed the need for comprehensive services (see Table 5). Comprehensive services for individuals with FASD require the involvement of the individual, family members, and multiple systems of care.

Individuals with FASD often have difficulty generalizing new information. When teaching children new skills, parents and teachers need to be involved to help generalize these skills in the child's everyday environment. Participants also indicated a need for parent education about FASD and training in advocacy and communication skills to effectively interface with various systems. Parents of children with FASD experience considerable stress and frustration managing their children's behavior and advocating for their needs and often benefit from support groups. Hearing that other people are struggling with similar difficulties helps parents feel they are not alone and provides a sense of hope that they can cope with these challenges.

Individuals with FASD often need services or supports from multiple service systems, including special education, developmental disability services, mental health, and specialized medical care. Many children with FASD do not easily qualify for special education or developmental disabilities services as their disabilities do not typically fit the recognized criteria or categories established by these systems. Parents often have to advocate for their children to receive services to meet their needs within these systems. Parents described seeking a variety of services such as special education (e.g., individualized education plans, 504 plans), speech, occupational, and physical therapies, counseling, respite, and case management services. In addition to the specific services listed above, participants emphasized that comprehensive services for individuals with FASD must include education and training on FASD for providers and teachers. Participants believe that when providers, teachers, and policy makers have greater knowledge and understanding of FASD, the availability and appropriateness of services for their children will improve.

Coordinated

Unfortunately, many individuals with FASD do not easily qualify for service coordination programs through developmental disabilities services or other specialized programs. The most common reason participants stated for not being able to qualify for services was children's IQ scores being too high (generally IQ > 70). Several families of children with relatively higher IQ scores were successful in obtaining developmental disabilities services, but they noted it took multiple appeals and advocacy to qualify. Families are often left feeling overwhelmed by the level of advocacy and coordination that is required of them to obtain and manage services for their children. Even for those individuals who do qualify, parents report coordinators are not always well informed about FASD and that considerable advocacy and coordination is still needed.

Participants expressed a need for a centralized service or coordinator specializing in FASD to assist in managing the various services provided to the individual with FASD and family. Some participants described a centralized agency that would offer and coordinate all of the services needed by the individual. Others suggested a single worker who was knowledgeable about FASD and could engage all of the relevant service providers and facilitate communication among them. Regardless of how the coordination of services is delivered, the coordinator needs to be both knowledgeable about FASD and have a complete understanding of existing service systems. In addition, parents prefer that the coordinator is a consistent person who is involved with the family long-term. The coordinator would be able to provide families guidance and advice as the child develops and assist with obtaining needed services at each developmental stage. Participants also valued a coordinator who could be available to families to assist with problem-solving or crisis intervention when needed and to provide support during more challenging periods. See Table 6 for supporting quotes for this theme.

DISCUSSION

The purpose of this study was to identify ideal characteristics of intervention programs to prevent secondary conditions in individuals with FASD. Parents of children with FASD and service providers are optimal sources for this information as they are knowledgeable about the day-to-day needs of this population and are the ultimate consumers of developed interventions (i.e., in terms of receiving and providing interventions, respectively). Results from this study yielded five primary characteristics of preventive interventions for this population. Specifically, interventions need to be available across the lifespan, focus on preventive strategies, be individualized, comprehensively address the needs of the individual and family, and be integrated and coordinated across components.

The five characteristics identified by participants are consistent with the positive behavior support (PBS) framework.[8-9] The PBS approach emerged from the blending of the practical science of applied behavioral analysis, the inclusion movement, and person-centered planning. It is most often utilized with individuals with developmental disabilities, especially within the school setting. The PBS approach primarily focuses on adapting the environment to enhance the individual's quality of life. The reduction of problem behaviors is a secondary goal. Carr and colleagues[8] identified nine critical features of the PBS approach including:

1) lifespan perspective,
2) emphasis on prevention,
3) a comprehensive lifestyle change and quality of life,
4) systems change and multicomponent intervention,
5) stakeholder participation (i.e., collaborative vs. expert-driven stance),
6) ecological validity (i.e., applicability of intervention to real-life settings),
7) social validity (i.e., intervention evaluated by stakeholders as resulting in meaningful change vs. objective measures),
8) flexibility with respect to scientific practices, and
9) multiple theoretical perspectives.

The first five critical features align well with the characteristics identified in the current study. The remaining features relate to the validity and evaluation of PBS interventions. A limited number of intervention programs have been developed and evaluated for individuals with FASD. The majority of intervention programs evaluated to date have been developed for children between the ages of 3 and 12 and have focused largely on single domains such as academic skills, behavior problems, social and adaptive skills, and aspects of executive functioning.[10] Intervention programs have generally emphasized environmental accommodations and skill building, which is consistent with the PBS approach. Many programs also incorporate a collaborative stance with families and some involve both parent and child components.

While there have been significant advances over the last decade in the area of intervention research for individuals with FASD, much work is needed. In line with the current study results and the PBS approach, intervention programs are desperately needed across the lifespan, especially during adolescence and adulthood. Systematic approaches that can guide intervention strategies over time are preferred to piecemeal interventions that lack coordination. Systematic approaches should also be flexible and allow for adaptations or new strategies to be introduced as new developmental challenges and environments are encountered. Interventions for individuals with FASD also need to be more comprehensive across targeted domains, settings, and time. Previous research has demonstrated that children with FASD can benefit from interventions targeting specific domains.[10] Incorporating these strategies into broader intervention programming may be helpful (e.g., targeting social skills, behavior, and educational support). Targeting multiple settings is also critical for generalization. An intervention employed only at school is unlikely to be as effective as strategies consistently utilized at school, in the home, and in the community. Multi-component interventions will likely be needed to target multiple domains and settings. Accumulating evidence is growing supporting the benefits of multi-component interventions.[11-12] Booster sessions or additional interventions may be needed over time to maintain intervention effects and promote positive trajectories.[12] This type of follow-up is especially relevant as children are faced with new developmental challenges. Strategies may need to be modified or new skills taught to help the child and family adapt to new challenges.

As is true in many fields, intervention research in FASD would benefit from trials with longer follow-up time points to learn about the sustained efficacy of intervention programs. Most intervention trials to date including children with FASD have presented only relatively short-term follow-up data (e.g., 3-months), if any. Funding is a major factor in the lack of longer-term follow-ups. Furthermore, follow-up assessments have typically only included children assigned to the intervention condition, as most studies have utilized delayed wait-list control groups in their design. Although there are many valid reasons for utilizing a wait-list control group design, it limits the conclusions that can be drawn regarding outcomes beyond immediate post-intervention. Follow-up assessments with only the intervention group provide information on whether scores on outcome measures were maintained across time, but the strength of this effect is unclear. The control group could have experienced changes (either positive or negative) post-intervention without the intervention. Longitudinal group comparisons are especially important when evaluating prevention effects as the primary aim is to prevent the onset or reduce the severity of the behavior. Without a comparison group, it is difficult to determine if the intervention had an effect over time (i.e., no change in the intervention group vs. increase in symptoms in the control group; both groups have similar decrease/increase in symptoms).

Implementing and evaluating interventions can be very challenging, especially within difficult funding climates in both research and clinical settings. Longitudinal evaluations of multi-component interventions are expensive and complex to manage. However, the need for such research is great, as is reflected in the findings from the current study. Dedicated and creative teams of researchers will be needed to undertake such work and secure funding from various sources. Multi-site studies may be necessary to amass large enough samples to more fully evaluate intervention effects. In addition, future trials comparing multi-component interventions versus single component interventions will provide important data that will be useful to agencies and policy makers regarding the cost-effectiveness of interventions offered to families. This data is very valuable for the dissemination of evidence-based interventions in the community.

Results from the current study should be evaluated within the context of the following limitations. Although 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 racial/ethnic backgrounds of parents in the current study also 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.

In summary, this study is the first to our knowledge to systematically investigate ideal program characteristics for the prevention of secondary conditions in FASD. We used a phenomenological approach to understand the lived experiences of service providers and parents of children with FASD and their unique perspectives on the program characteristics and intervention strategies that would be most beneficial for this population. The five program characteristics identified in this study are consistent with the PBS approach and suggest that well-designed intervention programs utilizing this approach may be suited to this population. Results from this study can be used to inform the future development of preventive interventions across the lifespan. Collaborative efforts from clinicians, researchers, funding agencies, and policy makers will be necessary to advance the rigor and availability of evidence-based preventive interventions for individuals with FASD.

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