

Educational Services for Youth with Fetal Alcohol Spectrum Disorder: Caregivers' Perspectives

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Abstract The purpose of this study was to identify services that caregivers of youth with fetal alcohol spectrum disorder believe would help youth with FASD succeed in school. Sixteen caregivers participated in telephone interviews that included the question: “What services would help youth be successful in school?” A concept mapping technique was employed, in which responses were grouped together by participants and the grouping data was analyzed using multidimensional scaling and cluster analysis. Six concepts emerged from the question about services, including the following: (1) being heard by educators, (2) FASD-informed educators, (3) involvement in child’s education, (4) resources and accommodations, (5) supportive knowledge base, and (6) support and understanding at home. Concepts were compared to the existing literature.

Keywords Fetal alcohol syndrome · FASD · Education · Caregivers · Youth · Needs · Services · Concept mapping

Fetal alcohol spectrum disorder encompasses a variety of conditions associated with maternal (pre-natal) alcohol consumption (Buxton 2009) and is associated with numerous deleterious effects including physical deficits in growth and height (Stromland 2004), observable structural damage to the brain such as agenesis of the corpus callosum or cerebellar hypoplasia (Stratton et al. 1996), diagnosable neurological impairments such as epilepsy (Chudley et al. 2005), and softer neurological impairments including impaired motor skills or hearing loss (Center for Disease Control 2004). Furthermore, fetal alcohol spectrum disorder (FASD) is associated with several functional impairments. Individuals with FASD often exhibit deficits in impulse control, social perception, communication, abstraction, cognition, and attention

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(Stratton et al. 1996). FASD-related deficits in executive functioning can cause problems with decision-making, impulsivity, and judgment (Malbin 2004).

As a result of these deficits, FASD poses several educational challenges. Although a great deal of research has investigated educational experiences for children with FASD (Adnams et al. 2007; Jirikowic et al. 2008b; Koren et al. 2009), research on the educational experiences of older youth and adolescents is limited. Children with FASD may present with low math scores or impaired cognitive functioning (Coles et al. 2011), but IQ scores in children affected by FASD fall within a wide range and many students with FASD have average or above-average IQ scores (Rasmussen 2005). Accordingly, educational difficulties are typically ascribed to deficits in functioning in areas such as planning, schedule-adherence, and organization (Siklos 2008) rather than to low IQ scores. The availability of services targeted specifically at meeting the needs of students with FASD varies widely between Canadian provinces, and existing educational supports often fail to account for the highly variant presentation of alcohol-related functional deficits (Naumann et al. 2013).

For adolescents, the effects of FASD often translate into difficult or disrupted school experiences. Streissguth et al. (1996) found that 70% of youth with FASD had experienced disruptions in their education, defined as suspension, expulsion, or dropping out. Furthermore, they found high rates of co-morbid disorders, with 60% of youth with FASD having been diagnosed with attention deficit hyperactivity disorder. Students with FASD were also found to place considerable stress on special education resources, with over 65% receiving remedial help in education and mathematics. Additional research by Howell et al. (2006) found that adolescents with FASD showed decreased performance on standardized math tests compared to a control group of adolescents from similar socioeconomic backgrounds. Taken together, the current research highlights the effects of FASD on adolescents' development and educational experiences and suggests a need to identify effective services, support systems, and other factors contributing to educational success for adolescents with FASD.

Despite the challenges associated with education, caregivers can have a strong impact on educational experiences for children and youth with FASD. Duquette and Stodel (2005) identified caregiver support as the most important factor contributing to perceived educational success. Moreover, Duquette et al. (2006) showed that caregivers' perceptions of educational success were correlated with actual educational persistence. Their findings showed that students whose caregivers saw them to be successful were more likely to view themselves as successful, and in turn were less likely to drop out or face expulsion. Streissguth et al. (2004) found that a positive home environment for youth with FASD was associated not only with improved educational persistence, but also with decreased involvement with the court system, abstinence from drugs and alcohol, and lower risk of developing secondary disabilities.

A review of the existing literature highlighted several areas in which services are needed to help youth with FASD succeed in their education.

Availability

Despite the prevalence and known impacts of FASD, there are limited services available targeted at improving the educational experiences of youth affected by the disorder. The diversity of learning difficulties faced by students with FASD contributes to the challenging nature of service development and implementation. In addition, research into effective educational service delivery for youth with FASD is modest.

FASD-Informed Services In recent history, educational institutions have generally acknowledged a duty to support students with complex disabilities by equipping educators with the tools necessary to meet their needs (Ryan and Ferguson 2006). In attempting to fulfill this obligation, educators face the challenge of navigating a constantly growing array of new and emerging disorders (Blackburn et al. 2010). Accordingly, there is a need for programs and services that address the needs of specific target populations of students with complex disorders. Furthermore, most North American educational systems recognize a need for students with disabilities to be included in the regular classroom setting along with their peers (Fitch 2002). Therefore, there is a demand for services that would support students with FASD in functioning and excelling in the regular classroom setting. Despite the demand for services, there has been little progress in service implementation and systematic training of educators targeted at improving educational outcomes for students with FASD (Ryan and Ferguson 2006).

Students with FASD present with unique learning difficulties that necessitate specially designed educational approaches. General theories of learning often fall short in understanding the learning strategies employed by these students (Blackburn et al. 2010). For example, students with FASD often have well-developed short term verbal recall and are able to “parrot back” items that have been taught to them without a full understanding of the item’s meaning (Mattson et al. 1996). This short-term verbal recall can make it difficult for educators to ascertain when students with FASD have gained a full understanding of the material. Accordingly, there is a need for services that recognize and address the challenge of assessing learning in students with FASD. Furthermore, students with FASD are often ineligible for general services targeted at students with special needs due to the fact that, despite their disability, testing may find their intellectual ability to be within the average range (Kalberg and Buckley 2007). Taken together, the current research highlights the need for services that will address the diverse needs of students with FASD in the context of the regular classroom.

Individualized Approaches Some common factors exist in the learning challenges faced by most students with FASD. Cognitive confusion, difficulty understanding the consequences of actions, and memory impairment represent some of the most common educational challenges for alcohol-affected students (Job et al. 2013). However, research has shown a great deal of diversity in the learning challenges associated with FASD. Abel and Sokol (1987) found no consistent pattern in the learning difficulties faced by students with FASD. Furthermore, depending on the severity and nature of impairment, FASD may have little effect on students’ cognitive functioning or learning abilities (Streissguth et al. 1991). Challenges to educational success often present in other ways such as hyperactivity, poor social functioning, or disruptive behaviors (Blackburn et al. 2010).

As a result of the wide array of educational challenges posed by FASD, services designed to address specific deficits often fail to meet the needs of students with FASD as a wider population (Duquette et al. 2006). Accordingly, research into services for students with FASD should focus not only programs targeted at overcoming specific challenges and deficits, but also aim to develop more general services that can address the needs of this student population at large. Moreover, behavior modification techniques employed by most educators are often ineffective when used on students with FASD, requiring educators to develop new strategies that respond to the learning abilities of individual students (Malbin 2007).

Delivery

Despite the diverse needs of students with FASD, some services and interventions have been developed with the intention of addressing educational needs common to most students with FASD. Recent research has focused on services targeted at delivering comprehensive learning assessments for students with FASD, the use of evidence-based interventions to improve educational outcomes, and professional development for educators.

Learning Assessment Although it is important for educators to know that a student in their classroom has been diagnosed with FASD, knowledge of a diagnosis is not sufficient for educators to meet the needs of individual students. Rather, due to the diversity of potential impairments associated with FASD, a comprehensive individual learning assessment is necessary to provide educators with the information needed to address the specific needs of a given student (Kalberg and Buckley 2007). Learning assessments typically garner information about a student from numerous sources including caregivers, educators, and direct observation of the student's learning processes (Olson et al. 1997). Collected information about students' ability to work independently, attentional capabilities, behaviors, strengths, interests, interactional abilities, and general functioning can then be used to develop an individual learning profile for use by educators in developing a learning plan suited to the individual needs of the student (Kalberg & Buckley). However, despite the variance in individual needs for students with FASD, some research has investigated specific strategies and interventions that may address the overarching needs of the majority of this student population.

Structured and Systematic Teaching A structured and predictable learning environment is an essential contributor to educational success for students with FASD (Streissguth 1997). Kalberg and Buckley (2006) explain the need for structure by drawing the analogy of the learning environment as an "external nervous system" for the student. In this analogy, structure in the student's learning environment can help to compensate for cognitive deficits in the actual nervous system.

Additional research by Kalberg and Buckley (2007) identified three particular types of structure that may facilitate learning experiences for adolescents with FASD: visual, environmental, and task structure. Visual structure was found to be particularly important for youth with FASD, and Kalberg and Buckley recommend taping off sections of the room as activity centers or using containers to separate materials as effective strategies. Environmental structure facilitates learning by establishing clear boundaries for what type of learning occurs in each part of the classroom and minimizes the chances of behavioral problems. For example, an educator could clearly delineate which areas of the classroom are to be used for mathematics, computers, reading, etc. Task structure can also be used to provide a clear system for the child to follow; educators may wish to use color coding to delineate the beginning, middle, and end of a task. Taken together, Kalberg and Buckley's evaluation of structure and systematic teaching demonstrates the need for services that enable teachers to organize their classrooms in ways that are conducive to facilitating learning for students with FASD.

Evidence-Based Interventions Research on evidence-based interventions for students with FASD is a growing field. Adnams et al. (cited in Riley et al. 2003) conducted a randomized controlled trial to evaluate the effects of Cognitive Control Therapy (CCT; a

therapy emphasizing the reorganization of immature cognitive processes in order to address FASD-related functional deficits) on learning and behavioral outcomes for students with FASD. Students receiving CCT for 1 h/week over the course of 10 months showed qualitative improvements in motivation, self-efficacy, school achievement, attitude to learning, and writing as evaluated by therapists and educators as compared to a control group. However, certain limitations of this study are notable: namely, although improvements in observed behavior were found, neuropsychological assessment found no evidence of improvement in any of the measured areas. Furthermore, the study consisted of a relatively small sample size of 10 children.

Soh et al. (2015) found that delivering Alert therapy (Williams and Shellenberger 1996), a 12-week program focused on sensory integration and cognitive behavioral interventions, to children with FASD resulted in an increase in gray matter associated with improved executive functioning (which could allow students to better regulate their behavior and engage in their education). Additionally, Kerns et al. (2010) found that a computerized attention training program resulted in improvements in selective and sustained attention in students with FASD. Kable et al. (2007) developed a Math Interactive Learning Experience program for children with FASD; this program focused on sociocognitive habilitation and was found to result in significant gains in knowledge as well as behavioral improvements. Taken together, the success of these evidence-based interventions in improving educational performance for students with FASD speaks to the need for service delivery in the form of targeted therapeutic interventions that directly address the needs of this student population.

Professional Development for Educators Due to the complexity of FASD and the highly individualized needs of those affected by the disorder, educators require specialized training to meet the needs of students with FASD (Blackburn et al. 2010). Although many FASD resources have been made available to educators (British Columbia Ministry of Education, Skills, and Training 1996; Healthy Child Manitoba 2009), until recently there had been no evaluation of the effectiveness of available resources. However, an Ontario-based study by Koren et al. (2013) investigated the effectiveness of the Motherisk FASD Clinic Module, an education resource and professional development session targeted at informing educators about the needs of students with FASD. They found an overwhelmingly positive reaction to the training module, with 79% of participants reporting that the module will improve their future job performance, 99% reporting that the training module was an important job resource that they would recommend to their colleagues, and 93% reporting increased confidence in their knowledge of FASD. Moreover, 75% of participants reported that this module was their first FASD-focused training experience, demonstrating a clear need for programs and services targeted at raising awareness of FASD among educators.

Additionally, Clark et al. (2014) investigated the effectiveness of the Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD), a professional development program aimed at ameliorating educators' understanding of the unique needs of students with FASD. Following delivery of the program, they found improvements in students classroom behavior as well as self-reported changes in educators' teaching practices (e.g. redefining student behaviors or adapting teaching practices to students' individual needs). This study provides further support for the potential benefits of ensuring educators receive professional development on FASD.

Purpose

The purpose of the present study is to identify, from the perspectives of caregivers of youth with FASD, the services needed to help them achieve their best in school. Caregivers of youth with FASD often report a great deal of frustration and difficulty with the education system (Chamberlain et al. 2017) and it is therefore important for research to investigate caregivers' insights into how the education system could be improved. Caregivers' unique insights into the needs of children in their care may be beneficial in identifying needs specific to youth with FASD that have not been identified in previous studies. Furthermore, this study focuses specifically on a Canadian population and school system, whereas most existing research in this area has been conducted in the United States.

Methodology

Participants

Caregivers in a medium sized central Canadian city which houses a diagnostic clinic and professional network that has some community supports in place were asked to identify what the educational system and their youth's school need to help their child be successful. The present study targeted adult participants who had experience raising a youth age 10 or older with suspected or diagnosed FASD, and who were willing to participate in a phone interview. Participants were recruited via advertisements distributed through community newsletters, professional networks and contacts of a diagnostic clinic serving individuals and families within and surrounding a medium sized Canadian city. Eligibility of participants who had cared for youth with a formal diagnosis was confirmed by an affirmative response to the question, while individuals with caregiving experience of a youth suspected of having FASD were asked additional screening questions. This research was overseen and approved by the institutional review board at the authors' institution.

Procedure

Concept mapping is the quantitative analysis of qualitative data (Trochim 1989). The final result of concept mapping is an easily-interpretable visual representation of a concept's organizational structure (Trochim 1989). The creation of a concept map can be used as a foundation for program planning and can help to introduce structure and objectivity into qualitative research (Burke et al. 2005). According to Trochim, concept mapping allows for an understanding of participants' lived experiences. Concept mapping uses ideas generated by a sample of participants to draw inferences about the organizational structures of ideas in a larger population.

The process of concept mapping consists of six steps: preparation, generation, structuring, representation, interpretation, and utilization. In the preparation step, the focal area of the study is determined and the criteria for selecting study participants are identified. During generation, participants generate a list of items/responses to the focal question that will then be used in the remaining steps. The structuring step consists of participants sorting the generated responses into groups according to perceived similarity. In the representation step, responses and sorting data are entered into specialized concept mapping software and data analysis is performed.

During interpretation, the results of the data analysis are discussed and the content of the data clusters is interpreted. Finally, in the utilization step, the findings of the research are examined in order to determine how they address the original research question. Each of these steps is discussed in more detail below.

Preparation The focal area for this study was determined to be caregivers of youth who had been diagnosed with FASD, or who were suspected to have FASD. In the case of youth who were suspected to have FASD, the Neurobehavioural Screening Tool (NST; Nash et al. 2006). Nash et al. developed the NST in response to the difficulty associated with obtaining a diagnosis of FASD. Numerous caregivers suspect they are raising a child with FASD, but lack access to diagnostic procedures; accordingly, Nash et al. designed the NST to support the suspicion of FASD based on an evaluation of a child or adolescent's behavior over a 6-month period. Nash and colleagues created the NST based on ten items from the Child Behavior Checklist found to predict FASD diagnosis. The NST is particularly suited to the purposes of the present study, because Nash et al. found it to be most accurate for adolescents between 12 and 17 years of age. For participants in this study, if the adolescent had been diagnosed with FASD, a copy of the diagnosis was requested. If the adolescent was suspected to have FASD, the NST (Nash et al. 2006) was administered. The NST was then scored by trained researchers, and participants were only included in the study if the NST indicated positive results for FASD.

Generation of Responses Consent to participate was obtained verbally at the beginning of each telephone interview. Participants were offered a small honorarium for each stage of the study in which they choose to participate. Caregivers were asked for demographic information as well as open-ended responses to seven interview questions, including: "What services would help youth be successful in school?" The other six questions were not directly related to the topic of this study and were used in other studies. Additional probing questions were not used. Interviews lasted approximately 45 min each. Participants also had the option to participate in a second response-sorting phase of the study. If participants chose to continue to this phase, their contact information was collected and stored securely to facilitate additional contact.

Structuring of the Responses Unclear or redundant response items were edited or removed by the researchers, relying on the researchers' existing knowledge in the area of FASD and on interrater agreement in order to identify redundant responses. Participants who volunteered for the second response-sorting phase of the study were asked to group the responses into more than one category and to have more than one response per group. Aside from those two criteria, response sorting was at the discretion of participants themselves.

Representation of Responses After responses had been sorted by participants, statistical software that employs non-metric multi-dimensional scaling and hierarchical cluster analysis was used to average the sortings and form distinct concepts. Each open-ended interview question was analyzed individually, producing two concept maps: one for the question on adolescents' needs in school, and one for the question on what caregivers need to help adolescents be successful.

Multi-Dimensional Scaling Multi-dimensional scaling uses the x-y matrix, and each participant's responses are represented in the matrix. Responses are represented either by a 0, indicating the responses sorted into the same group by that individual, or a 1, indicating the

response was sorted into a different group. Matrices are then combined into a summary matrix and plotted onto a point map. The distance between points on the map represents the average frequency of each item sorted with each other surrounding item.

Cluster Analysis In concept mapping, concepts that are more closely related to one another appear closer together on the map. Hierarchical cluster analysis was conducted to group individual statements into clusters that reflect related concepts. It is then the responsibility of the researcher to decide on the optimal number of concepts for the data by taking into account conceptual similarities/differences and bridging indices (Kane and Trochim 2007). A bridging index value was calculated for each response. These values, ranging from 0 to 1 reflected the degree to which that response bridged, or was sorted together with, other responses near to it on the map. A low bridging index, or less than 0.3 indicated that the response was often sorted only with other responses near to it on the map. A moderate bridging index, from 0.3 to .69, indicated that the response was occasionally sorted with responses in other areas of the map, and a high value, of .70 or greater indicated that the response was often sorted with responses in other areas of the map. Average bridging indices were also calculated for the bridging indices in each cluster. The validity of the analysis is measured by a stress value. Trochim (1989) noted that stress values below 0.35 indicate that a concept map is a valid representation of the sort data. The present map had a stress value of 0.32.

Interpretation In concept mapping, there is no single correct way to determine the appropriate number of concepts. Rather, researchers use past experience and knowledge to determine the optimal number of concepts for the set (Trochim 1989). A potential disadvantage of concept mapping can be found in the fact that all unique responses are equally represented, which results in researchers being unable to indicate which responses were most common or which were the highest rated (Brown and Bednar 2004). However, having participants reflect on and sort the data allows for more accurate participant-generated themes to emerge and helps to minimize the influence of the researcher (Burke et al. 2005). The final product of concept mapping is an easily interpretable visual representation of the organization of ideas.

Utilization Once a concept map has been created, its potential uses are limited only by the creativity and motivation of its users (Trochim 1989). One example of a common use for concept maps can be found in their use as foundational bases for program planning; once the relationship between ideas is understood, programs can be planned around the ways in which ideas interconnect (Burke et al. 2005). Participants can also be given the opportunity to challenge the results of the final concept map, and can find ways to incorporate the findings in their own lives (Kane and Trochim 2007).

Results

Participants were birth parents, adoptive parents, foster parents, aunts, or grandparents of youth over the age of 10 with FASD. Twenty caregivers were originally asked to participate, and four of these caregivers were excluded based on their child's Neurobehavioural Screening Tool results, leading to our final sample size of 16 participants. Participants had between 1 and 5 children in their households at the time interviews were conducted. Of the 16 participants interviewed, seven had household incomes under \$50,000 and none had household incomes

that exceeded \$100,000. Together, participants had been caregivers to 20 children with FASD (4 of the caregivers had 2 children with FASD in their care). All 16 participants took part in both the generation and structuring stages of the concept mapping procedure.

Following the analysis, researchers together determined the most appropriate number of concepts for the final solution and attached descriptive labels to each concept. Trochim (1989) found that, for concept maps with fewer than 100 responses, solutions comprised of between 3 and 20 concepts should be considered. Within-concept consistency of responses and discrepancy between concepts were used as the primary criteria for evaluating the validity of each solution. The default solution of 20 concepts showed clear evidence of fragmentation. Reducing the number of concepts to 10 did not sufficiently reduce this fragmentation. Significant reductions in fragmentation occurred when attempting nine, eight, seven, and six concept solutions, but the responses were still fragmented. The five concept model represented a good fit with the data. Four and three concept maps were reviewed, but further reduction from five concepts unnecessarily combined conceptually different content and created concepts that were over-generalized. The five concept solution provided the best interpretability (see Fig. 1). Reponses and bridging indices are presented in Table 1.

The most central responses within each concept were identified using individual bridging indices (i.e., the lowest individual bridging index within a concept represented the response most central to that concept’s content). These central responses were then used to provide guidance for concept labeling (Trochim 1989) by the researchers.

Discussion

There was a considerable amount of overlap between the concepts generated by participants in the present study and the ideas present in the existing literature. However, some notable differences were also found.

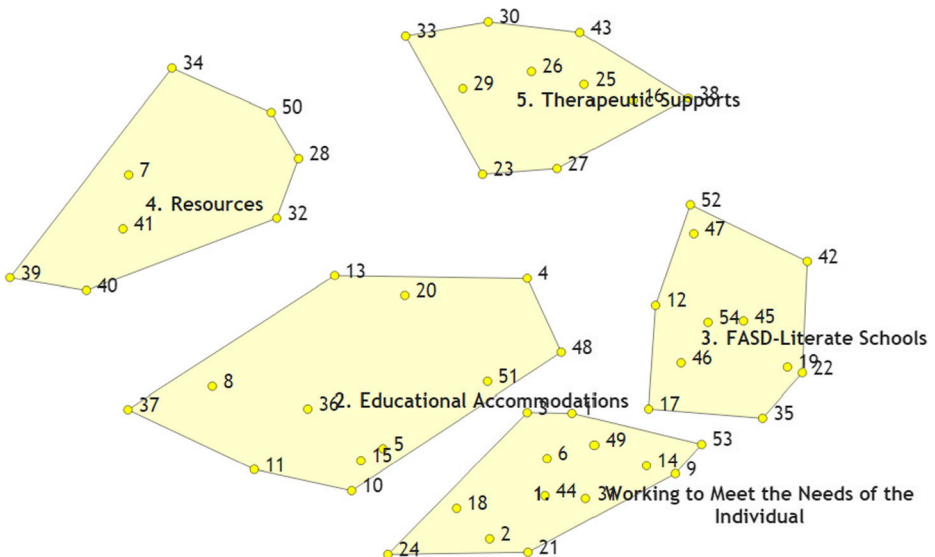


Fig. 1 Concept map: what services would help youth be successful in school?

Table 1 Responses and bridging values for concept map for question: what services would help youth be successful in school?

Concept and response	Bridging index
Working to meet the needs of the individual	0.21
1. One on one support	0.00
49. The right curriculum	0.02
3. Academic supports	0.03
14. Consistent educational assistant for the year	0.11
6. Advocacy for their needs	0.12
44. Staff who know exactly how to look after her	0.18
18. Flexible and individualized	0.23
24. Warnings about supply teachers and changes in class	0.24
9. Awareness by everyone	0.25
31. Principal leadership	0.25
2. A “go to” person at school	0.35
21. High supervision	0.40
24. Look at child’s values	0.58
Educational accommodations	0.40
51. Transition services for adolescents	0.10
48. Different form of testing	0.11
4. Access to special classroom	0.26
5. Accommodations	0.26
20. Safety plan	0.33
10. Body breaks to move around	0.35
15. Consistent staffing	0.41
36. Sensory training for self-management, self-soothing, and self-regulation	0.43
13. Community services should follow child into school	0.46
11. Child can excuse self if knows that going to have a meltdown	0.58
8. Alternative program	0.73
37. Separate entrance time	0.77
FASD-literate schools	0.32
17. Educational assistants who are not only into behavior modification and understand FASD	0.09
46. Tailor school to them	0.17
12. Community professional involvement	0.23
54. Individualized education plan	0.26
19. Formal recognition of FASD by system	0.32
45. Study skills that make more sense for them	0.33
35. Sensitive to differences within the disorder	0.35
22. In-house training in FASD	0.36
47. Teaching social skills	0.40
52. Tutor in school	0.49
42. Special services for FASD	0.56
Resources	0.83
32. Resource classroom	0.57
28. Ongoing supports	0.63
50. Training for parents	0.77
41. Special pencils	0.78
40. Special desk	0.92
34. Rural community resources less than city	0.99
7. After school program	1.00
39. Special classroom	1.00
Therapeutic supports	0.55
27. Occupational therapist assessments	0.42
23. Life skills	0.45
43. Speech therapy	0.49
30. Physiotherapy	0.51
25. Mental health class	0.56

Table 1 (continued)

Concept and response	Bridging index
29. Outdoor activities	0.58
16. Counselor	0.59
26. Mental health support	0.60
38. Social worker	0.62
33. Respite care	0.68

Working to Meet the Needs of the Individual

Responses within this concept focused on the need for educators and caregivers to work together to meet the unique needs of individual students with FASD. Many of the responses within this concept were consistent with findings from previous studies, but some specific strategies emerged that were unique to the present study.

Previous studies have addressed the highly individualized nature of FASD-related educational deficits. Abel and Sokol (1987) found no consistent pattern in the learning difficulties faced by students with FASD. Furthermore, Duquette et al. (2006) found that as a result of the wide array of educational challenges posed by FASD, services designed to address specific deficits often fail to meet the needs of FASD-affected students as a wider population. Responses within this concept such as “flexible and individualized,” “staff who know exactly how to work with her,” “the right curriculum,” and “look at child’s strengths” spoke to the need for educators to recognize the uniqueness of each student’s educational needs.

Although the general concept of meeting individual needs was consistent with the existing literature, the present study identified several specific strategies for meeting those needs that had not been addressed in previous studies. Responses such as “1 on 1 support,” “a go to person at school,” “high supervision,” and “consistent educational assistant for the year” spoke to the need for a single individual dedicated to understanding the needs of a specific student. Due to the complicated and diverse needs of students with FASD (Duquette et al. 2006), it is possible that a teacher tasked with educating an entire classroom of students could be unable to understand or meet the needs of a student with FASD, and therefore more individualized attention may be necessary. Furthermore, responses such as “principal leadership” and “warnings about supply teachers and changes in class” highlighted examples of practical steps that educators could take to ensure students’ individual needs are met.

Educational Accommodations

This concept focused on specific examples of educational accommodations that could help students with FASD succeed in the classroom. Although responses in this concept were consistent with the existing literature in that they recognized the need for specially tailored educational accommodations, this concept included several new examples of specific accommodations that were not explored in previous studies.

Most central to this concept was the idea of “transition services for adolescents.” In the context of being sorted with other responses within this concept, it is apparent that this

response highlights the need for educational accommodations that recognize the changing educational needs of adolescents as compared to children. Although a great deal of research has investigated educational experiences and support systems for children with FASD (Adnams et al. 2007; Jirikowic et al. 2008b; Koren et al. 2009), research on the educational experiences of older youth and adolescents is limited (Kalberg and Buckley 2006). Accordingly, the present study highlighted several specific educational accommodations that recognize the increasing autonomy and resulting shift in educational needs that accompany the transition into adolescence, including “child can excuse self- if going to have a meltdown,” “sensory training for self-soothing, self-management, and self-regulation,” “body breaks to move around,” “community services that follow the child into school,” and “separate entrance time.” Taken together, these responses highlight the fact that youth with FASD not only have unique individual needs, but may have more insight into their own needs and be capable of some level of self-regulation.

Streissguth (1997) highlighted the need for a structured and predictable learning environment. Kalberg and Buckley (2006) explain the need for structure by drawing the analogy of the learning environment as an “external nervous system” for the student. In this analogy, structure in the student’s learning environment can help to compensate for cognitive deficits in the actual nervous system. The response “access to a special classroom” in this concept may speak to the need for such accommodations, or may also encompass additional accommodations that may be present in a FASD-equipped classroom such as “different form of testing,” “safety plan,” “consistent staffing,” or “alternative program.” Taken together, the responses in this concept represent several examples of potential educational accommodations that could help adolescents with FASD succeed in school, and which were not present in a review of the existing literature.

FASD-Literate Schools

Responses contained in this concept focused on the need for educators to be aware of how FASD affects students’ ability to function in school, and to actively use that knowledge to improve students’ educational experiences. Ideas in this concept were largely consistent with the existing literature, but also included several novel responses.

Most central to this concept was the idea of “educational assistants who are not only into behaviour modification and understand FASD.” This idea is consistent with Malbin’s (2007) finding that behavior modification techniques are often ineffective for students with FASD. However, responses in this category identified alternate strategies for managing the behavior of students with FASD that were not present in the existing literature, including “teaching social skills” and “community professional involvement.” By consulting community professionals with expertise on FASD in an effort to improve their own FASD-literacy, educators may be able to recognize and employ alternate strategies such as working on children’s social skills that could help to manage maladaptive behaviors without relying on behavior modification techniques. Furthermore, professional development focused on FASD may improve educators’ FASD-literacy and ability to meet students’ learning needs, in line with Clarke et al.’s (Clark et al. 2014) findings.

Because of the diverse nature of FASD-related impairments, some knowledge about FASD must be generated on the individual level. Although it is important for educators to know that a student in their classroom has been diagnosed with FASD, knowledge of a diagnosis is not sufficient for educators to meet the needs of individual students. Rather, due to the diversity of

potential impairments associated with FASD, a comprehensive individual learning assessment is necessary to provide educators with the information needed to address the specific needs of a given student (Kalberg and Buckley 2007). The responses “individualized education plan,” “tailor school to them,” and “sensitive to differences within the disorder” highlighted ways in which knowledge of a student’s specific needs could result to educational plans that are tailored to the individual.

FASD has not been officially recognized as an exceptionality within the Ontario public education system (Naumann et al. 2013). As a result, although many Ontario youth with FASD are assigned individual education plans, they often do not qualify for other resources targeted at youth with disabilities due to the relatively invisible nature of their disorder (FASD ONE Intervention and Support Working Group, 2010). The response “formal recognition of FASD by the system” spoke directly to this deficit in recognition. The inclusion of this response within the concept of FASD-Literate schools implies that increasing FASD literacy in Ontario’s education system may help to facilitate formal recognition of the disorder as an exceptionality.

Resources

In this concept, caregivers described specific resources that could help to improve educational experiences for youth with FASD. Some responses contained within this concept were congruent with the existing literature, but several new ideas emerged as well.

Most central to this concept was the idea of a “resource classroom.” Research by Kalberg and Buckley (2007) describes several ways in which classroom settings could be adjusted to provide visual, environmental, and task structure for students with FASD. The responses “resource classroom” and “special classroom” contained within this concept are consistent with the idea of adapting classrooms to meet the needs of students with FASD, but several other responses in this concept provide examples of resources that have not been described in the existing literature. “After school program,” “special pencils,” and “special desk” are examples of resources that were not found in a review of the current research. These ideas are notable for their specificity, possibly suggesting that caregivers’ unique insight into the needs of youth in their care allowed them to identify classroom resources that were not readily apparent to researchers in the past.

Also present within this concept was the idea of “training for parents.” Research by Olson and Montague (2011) suggests that education on FASD can help caregivers to reframe problem behaviors by understanding that they are rooted in neurological impairments, which in turn can help caregivers develop a more positive view of children in their care and to feel more effective in their parenting. Furthermore, Brown et al. (2007) found that foster parents who are unaware that a child in their care has FASD or who lack information on FASD-related impairments often struggle to understand their child’s behaviors and have difficulty finding ways of managing those behaviors. The findings of the present study in regards to educating caregivers are congruent with the existing research.

Also present within this concept was the idea that “rural community resources [are] less than city [resources].” This is an idea which was not found in a review of the existing literature, and suggests that rural communities may not be as well-equipped as urban communities when dealing with the educational needs of youth with FASD. This idea may have emerged in the present study due to caregivers’ direct insight into their children’s educational experiences in urban and rural settings.

Therapeutic Supports

Responses contained within this concept spoke to the need for various forms of therapy and related supports that may improve educational experiences for youth with FASD. Although the general idea of therapeutic support was present in the existing literature, several specific forms of therapy emerged as novel responses.

Several potential forms of therapy for youth with FASD have been addressed in past studies. Shepard and Breen (2007) suggest that counseling based on Social Cognitive Career Theory (SCCT) can help adolescents with FASD overcome low self-esteem, difficulties in establishing routines, information processing challenges, and passive learning styles. Furthermore, Adnams et al. (2001) found that Cognitive Control Therapy resulted in improvements in motivation, self-efficacy, school achievement, attitude to learning, and writing as evaluated by therapists and educators for youth with FASD. Responses within this concept including “counselor” and “mental health support” spoke to the need for psychotherapeutic interventions that could help youth with FAS succeed in their education.

Several additional forms of therapeutic supports also emerged as responses, including “occupational therapist assessments,” “speech therapy,” “mental health class,” “physiotherapy,” and “social worker.” Although past research has focused on ways in which similar therapeutic supports could be beneficial for those with FASD (Jirikowic et al. 2008a; Popova et al. 2014a, b; Stark et al. 2015), none of these studies focused specifically on how these therapeutic supports could be beneficial in an educational context. This suggests that future studies may seek to explore the impact of various therapeutic supports on educational experiences for youth with FASD.

Limitations

All voluntary research is biased in that it selects for people with knowledge, characteristics, or lifestyles which make them more willing to participate compared to those who do not. It is also possible that selecting one caregiver in a household over another as a participant may result in a bias. Different caregivers within the same household may hold opposing views on caregivers’ needs in helping youth succeed in school or what services would help youth succeed in school. For example, men and women often have different parenting styles (Stephens 2009), and therefore selecting for one caregiver over another may result in different opinions on matters related to caregiver roles in ensuring educational success. Future research in this area may seek to interview both or all caregivers in a given household and examine differences in responses.

Participants in this study had prior contact with FASD supports and services. The fact that these families are aware of the disorder and have been in contact with services in their community may differentiate them from other caregivers of children with FASD who are unaware that children in their care have the disorder, or who have not engaged with resources in their communities. Future research may seek to engage with caregivers who had not previously been aware of their child’s disorder and who had not had previous contact with services, possibly through the use of the Neurobehavioural Screening Tool (Nash et al. 2009) to screen a random sample of the population (although ethical implications such as the impact of diagnosis on the child and family would need to be carefully considered). Additionally, all participants in the present study resided in southern Ontario. This focus on a particular geographic location may mean that these results do not generalize to caregivers of youth with FASD in other areas. Future research may seek to investigate whether these findings generalize

to other areas within and outside of Canada. Willingness to participate in a study, the caregiver selected as a participant, and prior contact with FASD supports and services are all unique features of the present study's sample.

Conclusion

Results of the present analysis were mostly congruent with findings in the existing literature. Past studies have also spoken to the need for educators to work toward meeting the diverse needs of individual students with FASD rather than adopting a “one-size-fits-all” approach. There was also considerable overlap between the present study's findings and past research on the necessity of educational accommodations that meet the needs of youth with FASD. Similarly, the idea of ensuring that those involved in the education system are FASD-literate has been noted in past studies. Lastly, the ideas of ensuring adequate resources are available in the classroom and providing therapeutic supports to students with FASD emerged in both the existing literature and the present study.

Although there was considerable overlap between the existing literature and the findings of the present study, several new ideas also emerged from the present analyses. Caregivers' idea of a single, consistent individual dedicated to assisting with a student's education throughout the school year had not been noted in previous studies. Additionally, caregivers in this study provided specific examples of resources such as “special desks” that had not been noted in past studies, which mostly focused on broader ideas of resources. Furthermore, the idea of incorporating therapeutic supports such as occupational therapy and physiotherapy in the context of students' education emerged in this study. Although past studies have explored the therapeutic benefits of such supports for individuals with FASD, these supports have not been studied as a means of supporting students with FASD to succeed in their education. Future research could seek to evaluate the effects of various therapeutic supports on student academic performance.

There was a notable lack of examples of specific evidence-based therapeutic interventions in the responses provided by participants. This may indicate that further work is needed to disseminate information on evidence-based interventions to caregivers. Caregivers in the present study spoke more broadly to the need for psychotherapeutic supports as well as other types of supports such as speech therapy and physiotherapy. It is possible that, although caregivers are generally aware of the need for psychotherapeutic support, many may not be aware of specific therapeutic modalities that have been found to be effective and may instead rely on experts in the field for direction in this area.

Research and practice need to capitalize on caregivers' unique insights into the educational needs of children in their care. Research in the area of educational needs of students with FASD has most frequently been conducted in the United States. Although Canada and the United States share many similarities, culture differences and differences in educational systems create the necessity to understand differences in Canadian students as a unique population. By learning more about the educational needs of students with FASD, educators and caregivers can better prepare themselves to understand and meet the needs of this diverse and challenging population.

Future research in this area may seek to capitalize on the novel ideas provided by caregivers in this study. Specifically, investigation as to the effects of occupational therapy or physiotherapy supports on students' learning outcomes could prove beneficial. Similarly, research could be

undertaken into the effects of having a consistent support person available throughout the school year for students with FASD. Lastly, future studies could seek to investigate methods of disseminating information on evidence-based interventions to caregivers.

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