



Hipatia Press
www.hipatiapress.com



Instructions for authors, subscriptions and further details:

<http://qre.hipatiapress.com>

Toward Better Collaboration in the Education of Students with Fetal Alcohol Spectrum Disorders: Integrating the Voices of Teachers, Administrators, Caregivers, and Allied Professionals

Jenelle Marie Job, Cheryl Anne Poth, Jaqueline Pei¹, Belina Caissie², Deborah Brandell, & John Macnab³

- 1) School of Psychology, University of Alberta, Canada
- 2) Edmonton Regional Educational Consulting Services, Canadá
- 3) Edmonton Public School Board, Canadá

Date of publication: February 28th, 2013

To cite this article: Job, J. M., Poth, C. A., Pei, J., Caissie, B., Brandell, D., & Macnab, J. (2013). Toward Better Collaboration in the Education of Students with Fetal Alcohol Spectrum Disorders: Integrating the Voices of Teachers, Administrators, Caregivers, and Allied Professionals. *Qualitative Research in Education*, 2(1), 38-64. doi: 10.4471/qre.2013.15

To link this article: <http://dx.doi.org/10.4471/qre.2013.15>

PLEASE SCROLL DOWN FOR ARTICLE

The terms and conditions of use are related to the Open Journal System and to Creative Commons Non-Commercial and Non-Derivative License.

Toward Better Collaboration in the Education of Students with Fetal Alcohol Spectrum Disorders: Integrating the Voices of Teachers, Administrators, Caregivers, and Allied Professionals

Jenelle Marie Job
University of Alberta

Cheryl Anne Poth
University of Alberta

Jacqueline Pei
University of Alberta

Belina Caissie
Edmonton Reg. Ed. Consulting Services

Deborah Brandell
Edmonton Public School Board

John Macnab
Edmonton Public School Board

Abstract

This exploratory study addresses the call for an increased presence of key stakeholders' perspectives in educational research involving students with Fetal Alcohol Spectrum Disorders (FASDs) (Duquette, Stodel, Fullarton, & Hagglund, 2006a). Specifically, greater understandings are necessary to support the educational success of students with FASDs. The analysis of 11 focus groups and 3 interviews with teachers, administrators, caregivers, and allied professionals (total n = 60) revealed three themes: fostering relationships, reframing practices, and accessing supports. These findings have important implications for the use of a qualitative approach in generating evidenced-based educational practices for stakeholders reflective of enhanced communication and collaboration that better meet the needs of students with FASDs.

Keywords: Fetal Alcohol Spectrum Disorders, collaboration, evidence-based practice, home-school, focus group

2013 Hipatia Press
ISSN 2014-6418
DOI: 10.4471/qre.2013.15



Hacia una Mejor Colaboración en la Educación de Estudiantes con Desordenes por Síndrome Alcohólico Fetal: Integrando las Voces de Profesores, Administradores, Cuidadores y Otros Profesionales

Jenelle Marie Job
University of Alberta

Cheryl Anne Poth
University of Alberta

Jacqueline Pei
University of Alberta

Belina Caissie
Edmonton Reg. Ed. Consulting Services

Deborah Brandell
Edmonton Public School Board

John Macnab

Edmonton Public School Board

Resumen

Este estudio exploratorio aborda la necesidad de una mayor presencia de las partes interesadas en la investigación educativa que implica a estudiantes con Desordenes por Síndrome Alcohólico Fetal (DSAF) (Duquette, Stodel, Fullarton, & Hagglund, 2006a). En concreto, para un mayor entendimiento es necesario apoyar el éxito escolar de estudiantes con DSAF. En el análisis de 11 grupos de discusión y 3 entrevistas con profesores, administradores, cuidadores y otros profesionales (total n = 60) se revelaron tres temas: relaciones de acogida, nuevas prácticas de referencia y acceso a ayudas. Estos resultados tienen importantes implicaciones para el uso de un enfoque cualitativo en la generación basada en evidencias sobre las prácticas educativas que reflejan una mayor comunicación y colaboración que mejor satisfagan las necesidades de los estudiantes con DSAF.

Palabras claves: Desordenes por Síndrome Alcohólico Fetal, colaboración, práctica basada en evidencias, hogar-escuela, grupo de discusión

Fetal Alcohol Spectrum Disorders (FASDs) posing significant health, social, and educational concerns are among the most common yet preventable developmental disabilities (Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008). FASDs result from maternal alcohol consumption during pregnancy and have implications for the affected child, family, and community due to lifelong deficits in several domains of brain function (Chudley et al., 2005; Streissguth et al., 1994). Affected functions include cognition, executive function, adaptive and social skills, attention, memory, language, motor coordination, and mental health (Burd, Klug, Martsolf, & Kerbeshian, 2003; Connor & Streissguth 1996; Kelly, Day, & Streissguth, 2000; Rasmussen, 2005; Pei, Denys, Hughes, & Rasmussen, 2011). Health Canada (2006) estimates that more than 3,000 Canadian babies are born with FASDs every year, and 300,000 people are currently living with some form of the disorder. Given the prevalence of this condition, it is essential that caregivers, health professionals, and school personnel are equipped to respond to needs associated with the deficits of prenatal alcohol exposure (PAE), and begin to work together on strategies to support students with FASDs achieve academic, social, emotional, and behavioral goals (Green, 2007).

Among the most pressing issues is the need to increase the capacity for school-based personnel and allied professionals to respond collaboratively to student needs (Blackburn, Carpenter, & Egerton, 2009). School personnel including administrators, teachers, support staff will undoubtedly interact with students with FASDs in their schools and classrooms and consult with allied professionals (e.g., psychologists, social workers, physicians, and community organizations) for assessment, instructional planning, and ongoing support. One of the challenges faced by teachers and administrators is that the significant learning, social, and behavioral difficulties of students with FASDs are often beyond their scope of experience. The lack of familiarity with affected students — combined with a paucity of educational and professional development opportunities on FASDs — often leaves

teachers without strategies to guide them in providing suitable educational opportunities (Carpenter, 2011).

Considerable efforts to identify and describe the clinical characteristics of children with FASDs have been undertaken, yet the existing systematic research on educational needs and effective academic strategies for students with FASDs is limited (Ryan & Ferguson, 2006a, 2006b; Streissguth et al., 1991). The majority of studies lack consideration of long-term consequences for adaptive behavior and learning, instead focusing on the presented intellectual functioning of children with FASDs (Streissguth et al., 1991). In light of the widespread presence of FASDs in our schools, it is disquieting that the little research that exists has not been solution-focused; as doing so would help guide the provision of appropriate educational programming supporting children with FASDs (Purdey, 2006).

The lack of FASD-specific learning opportunities within initial teacher education programs and subsequent in-service professional development initiatives is worrisome (Blackburn et al., 2009; Carpenter, 2011; Pei, Job, Poth, O'Brien-Langer, & Tang, 2012). These educational opportunities are essential for enhancing the extent to which teachers are prepared for integrating students with FASDs into the classroom, as well as educating youth on the consequences of maternal alcohol consumption during pregnancy (Blackburn, Carpenter, & Egerton, 2010). Recent research yields evidence of limited FASD awareness and knowledge among United Kingdom (UK) educators (e.g., Blackburn, 2009; Blackburn et al., 2010). In a study of 161 early childhood practitioners, 78% reported little to no knowledge about FASDs and maternal alcohol consumption (Blackburn, 2009) — a startling finding given that 40% of early education settings in the UK report supporting children with a range of needs associated with FASDs. These findings highlight the realistic challenges faced by practitioners tasked with providing educational programming yet possessing inadequate knowledge: "...because there's so little understanding and awareness about FASDs...it would be difficult for staff to plan for these students because they haven't had the training to support them" (Blackburn, 2009, p. 21). This study underscores the need for a knowledge base related to the unique learning needs of students with FASDs if teachers

are to provide appropriate accommodations (Ryan & Ferguson 2006a, 2006b). An essential first step within the Canadian context is to speak with teachers about their knowledge of and experience with affected students (see, Pei et al., 2012). Only then can we begin to bridge the gap between knowledge and effective educational programming for students with FASDs.

Given appropriate environments and supports, many students with FASDs graduate from high school and go on to lead quality lives (Duquette, Stodel, Fullarton, & Hagglund, 2007; Green, 2007; Ryan & Ferguson, 2006a, 2006). Academic success depends on caregivers and school personnel to create a good match between ability and programming (Duquette Stodel, Fullarton, & Hagglund, 2006b). Indeed, the National Organization on Fetal Alcohol Syndrome—South Dakota (NOFAS-SD) (2009) identifies that:

A team approach will help classroom teachers meet the complex needs of students with an FASDs. Successful collaboration involves teachers, parents, students and administrators, as well as community service providers from areas of mental health, social services and developmental disabilities. Membership in this collaboration should be flexible and draw on all expertise available in the school and surrounding community. (p. 13)

While caregivers can help with advocacy and modeling, school personnel and allied professionals can be influential by creating and following individual education plans (IEPs), establishing smooth transition plans, and collaborating with caregivers (Duquette et al., 2006a). Involvement of communities may include partnering with schools to develop work experience opportunities, post-high school transition, and school-to-work programs (Mellard & Lancaster, 2003).

The call for collaboration among school personnel and families of students with FASDs has been sounded before; indeed, Streissguth (1997) noted the need for a committed group of professionals to fulfill roles designed to enhance achievement among students with FASDs. She advocated for school-based fetal alcohol syndrome support teams that would meet regularly to discuss students' individual learning styles and ways to increase advocacy support as well as collaborate with

caregivers and coordinate with community professionals and organizations. The creation of such teams lends support to literature that argues that professionals connected to child welfare, healthcare, and education may play significant roles in the lives of affected students and their families (Brown, 2004). In addition to a commitment to collaborate, involved professionals must have comprehensive knowledge of alcohol effects and relevant local resources (McCarty, Waterman, Burge, & Edelstein, 1999) as well as respect and empathy for families of students with FASDs (Williams, 1999).

It is well established that awareness, education, and collaboration are key to improving the educational outcomes for students with FASDs (Blackburn et al., 2010; McCarty et al., 1999; Streissguth, 1997). And yet, no study has examined how these elements interact in practice. It is believed that discussion with key stakeholders (i.e., caregivers, school personnel, and allied professionals) involved in the support of affected students will bring about greater understanding of how collaborative teams work together. Necessary to understanding these interactions is information contributed by each stakeholder as this enhances the potential to create quality programming for students with FASDs.

Purpose & Objectives

The present study is part of a larger program of research focused on improving educational practices for students with FASDs. This paper reports the findings from the initial phase: a qualitative study of perceptions, experiences, and aspirations of teachers, administrators, caregivers, and allied professionals supporting students with FASDs across school, home, and community settings. Of particular interest was documenting the successes and challenges in stakeholder communication and collaboration within and across roles in an effort to better understand how to build and maintain positive working relationships.

To this end, the study was guided by the following objectives: (a) capture the experiences of teachers, administrators, caregivers, and allied professionals involved in the education of students with FASDs; (b) identify successful strategies for effective communication;

(c) generate evidence-based practices related to ways in which collaborative processes can lead to positive impacts for students, classmates, and teachers; and (d) highlight key areas for future research.

Methods

With the aims of exploration and theory generation, qualitative methods (i.e., focus groups and interviews) were appropriate for gaining a comprehensive understanding of stakeholder perspectives. Trustworthiness and confidence in the data was enhanced by the use of verbatim transcripts, member checking, and multiple coders (Merriam, 2009; Patton, 2002).

Participants

A total of 60 individuals participated in the present study including 31 teachers, 7 administrators, 16 allied professionals, and 6 caregivers. Teachers reported expertise in special education, a mean of 13.2 years experience (range 1-32 years), and represented all levels of instruction (7 identified as Kindergarten to grade 5, whereas 24 identified as grade 6 to 12). Administrators had a mean of 22 years experience (range 15-30 years) and held various roles (2 principals, 4 assistant principals, and 1 head of student services). Allied professionals reported a mean of 10.9 years experience (range 1-25 years), with the majority (12) identifying their roles as educational assistants and the remaining as other (i.e., in-home consultant, reading specialist, guidance counsellor, and manager of the school's Academy of Reading & Math Programs). Caregivers consisted of 2 maternal grandmothers, 3 foster mothers, and 1 adoptive mother. Their mean years experience ranged from 6 to 43 with a mean of 17.8 years. The age range for affected children with whom the stakeholders worked was 3 to 18 years.

Data collection

Participant recruitment was ongoing from March 2009 to May 2010 through established clinical networks via email and telephone, using

snowball sampling. Allied professional and caregiver participants were identified through their involvement with local FASD networks and programs. Administrator and teacher participants were identified based on FASD student populations. For selection, participants were required to meet all of the following criteria: (a) experience with a student with an FASD; (b) involvement in that student's psychoeducational or neuropsychological assessment (e.g., completing forms, providing an interview, and/or being provided with assessment results); (c) working with that student in the classroom or having knowledge of his/her classroom experience; and (d) communicating with caregivers, administrators, teachers, and/or allied professionals in support of successful outcomes.

In total, 11 focus groups and 3 individual interviews were held. Participants were grouped together according to role with the exception of one multi-role group (i.e., teachers, caregivers, and allied professionals) due to scheduling issues and travel distance. Given the familiarity and comfort of participants with one another, it is believed responses were candid and honest. Interviews (i.e., 1 administrator and 2 caregivers) were also the result of scheduling difficulties. Each session lasted approximately 1 hour and followed a semi-structured protocol, with minor adaptations to account for differences in experience between roles. For example, the question, "What supports outside the school system have you accessed to help your child?" was asked solely of caregivers to provide information about community supports and resources (see Table 1). The number of focus group participants ranged from 2 to 9 with a mean of 6. The focus groups and interviews were facilitated by two doctoral-level research assistants (one interviewer and one note-taker) with advanced training in qualitative research methods and analysis. Discussions were audio recorded and transcribed verbatim, and a preliminary analysis generated summaries that were distributed to participants electronically as a means of member checking (Creswell, 2012). Participant feedback and additional comments were incorporated as notes in the transcriptions to ensure accuracy of the data and completeness of participant response.

Table 1
Focus group and interview questions

Objectives	Question	Probes
A) Capture experiences of key stakeholders	Caregivers: What have been your child's experiences in the classroom?	a. What type of classroom is he/she in? b. What types of supports does your child need and are these provided in the classroom or in the school? c. What are a few key challenges your child faced academically and what strategies were implemented by his/her classroom teacher to help overcome these challenges?
B) Identify strategies for effective communication	Caregivers: How would you describe your relationship with your child's teacher(s)? Principal? Specialists?	a. Is there any preparation and/or training that you think teachers should have that would be beneficial to their work with your child and other children with FASD?
C) Generate evidence-based practices	Caregivers: What supports outside the school system have you accessed to help your child? (Academically, socially, behaviourally, emotionally?)	
A) Capture experiences of key stakeholders	Caregivers: Do you know other caregivers in similar situations and how do their experiences compare to your own?	
C) Generate evidence-based practices	Teachers, Administrators, & Allied Professionals: Think of a moment when you thought "yes, this strategy is working" with a students with FASD:	a. Describe the events that proceeded b. Describe the event itself — how did you know it was successful? c. Describe what happened next for you, the student, and his/her teacher

D) Highlights areas for future research	Teachers, Administrators, & Allied Professionals: Think about a time when you experienced challenges working within the classroom (either by yourself or as an aid to the classroom teacher) with a students with FASD:	a. Describe the events that proceeded b. Describe the event itself c. Describe what happened next for you, the student, and his/her teacher
D) Highlights areas for future research	Teachers, Administrators, & Allied Professionals: What issues are most pressing for a teacher, allied professional, or administrator working with a students with FASD?	
A) Capture experiences of key stakeholders	Teachers, Administrators, & Allied Professionals: What are three adjectives that describe what you think about or how you feel when you are told you will. have a students with FASDs in your school for the year?	
B) Identify strategies for effective communication	Teachers, Administrators, & Allied Professionals: What are your expectations of a students with FASD in the classroom?	

Data analysis

The analysis was undertaken in three phases: individual focus groups and interviews, across focus groups and interviews of the same role, and finally a cross-analysis of focus groups and interviews and roles.. During the first phase, an inductive process was used for generating codes for one transcript, and then used across transcripts within the same role. Coding was completed independently by two research assistants. The coders read each transcript three times, focusing on different aspects of the data each time: 1) highlighting information relevant to the research questions; 2) highlighting information related to underlying issues and concerns (e.g., awareness of professional identity or excuses made on behalf of a

child with FASD); and 3) assigning codes to the information highlighted in readings 1 and 2. With completion of the coding process, the summaries of each transcription were reviewed to compare themes and ideas. The analysis followed an iterative process, meaning that coding was informed by previous and subsequent transcription and summary readings.

In the second phase, similarities and differences between code lists for each role were compared and an inter-rater reliability of 90% was achieved. Codes were then discussed until consensus was reached. Cross analysis in phase three highlighted similarities within each role and differences across roles. This allowed for further streamlining of the coding list and identification of themes and subthemes (see Figure 1). A second review of the transcripts and coding system was conducted, and confirmability (i.e., the degree to which the themes were grounded in the data) and dependability of the data was discussed (Lincoln & Guba, 1985).

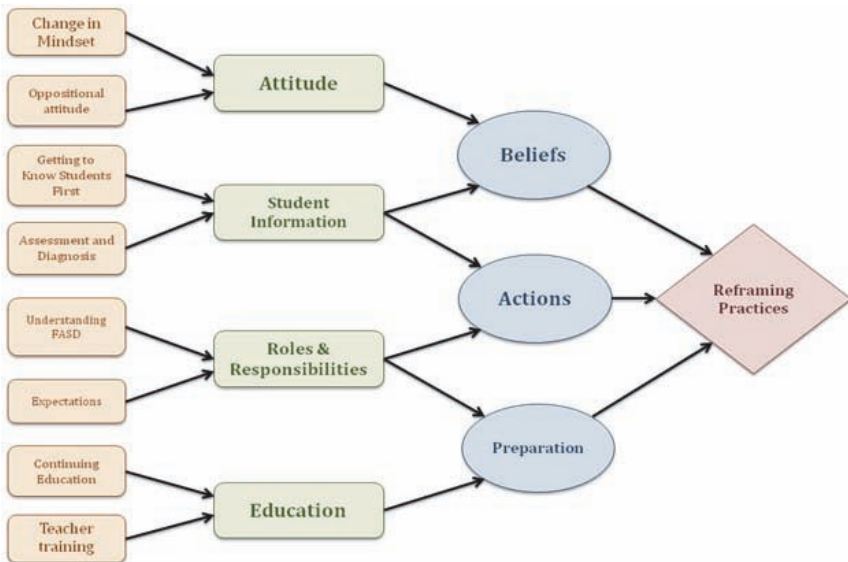


Figure 1. An example of code and theme development across roles

Findings

The cross-analysis yielded three major themes: *fostering relationships*, *reframing practices*, and *accessing supports*. The following section is organized by each of these themes with subthemes illuminating key components.

Fostering Relationships

The *fostering of relationships* emerged as a necessary condition for enhancing communication and collaboration between school personnel and families. The theme was particularly reflective in issues of respect and candid communication.

Respect. Both caregivers and allied professionals reported the need for an approach to building relationships that recognized and respected the contributions caregivers make to their child's educational experiences. Bob, an allied professional, described his approach for engaging caregivers by demonstrating respect at home: "This is their turf and I don't [want to] go in there and impose my will on [them]." Bob described his means of engagement as follows:

I invite them to go for a walk with me down a slightly different path. I love having access to the parents because I can model for them. They can see their child being successful [rather than] always being a problem...it's not necessarily always easy working with parents but it can be really rewarding.

Bob's approach is founded on the belief that engaging caregivers in conversation about their children encourages them to contribute their perspectives of the home environment. However, many caregivers did not report receiving respect in this way. Instead, they described interactions with school personnel where their perspectives were not sought and was interpreted as a lack of respect. Chloe, a caregiver, remarked: "...you can see [the child's] frustration but to relay that to the school is [hard]...you always either come off as the overprotective parent or...as making a mountain out of a molehill...so you're not always heard as you should be...."

Administrators and teachers, on the other hand, reported a need for caregivers to respect the expertise offered by school personnel and their desire for implementing consistent strategies between home and school environments. In particular, school personnel described challenges around caregiver cooperation in maintaining consistent learning and behaviour strategies. Callie, a teacher, described the need for an approach characterized by a shared responsibility between home and school: “if the child goes home or comes to school and plays one against the other...who benefits? Who does not have to be responsible?” Demonstrating a personal interest in the education of specific students with FASDs was seen as key to preserving consistency across domains and enhancing collaboration between caregivers and school personnel.

Candid Communication. A call for greater transparency (i.e., openness and honesty in process and educational practice) and enhanced communication among caregivers and school personnel emerged across all roles. Caregivers and teachers agreed that early and frequent communication between home and school benefited students with FASDs. Darlene, a caregiver, described how she went about employing such an approach: “...I like dealing with the teacher beforehand...I say ‘okay, this is what works, this doesn't work...and we need to work together’...I make that very plain from the beginning that we are in this together.” This strategy exemplifies the contribution the caregiver perspective can make in building a mutually supportive environment. Although most teachers, administrators, and allied professionals concurred that consistent communication with caregivers enhances the educational process for students with FASDs, some participants reported that not all caregivers are interested in engaging in conversation. Catia, a teacher, illustrates this viewpoint: “...Some parents aren't on board at all and aren't very supportive and then we have the other ones...that would do anything for their kids...” These findings point to the need for a willingness for caregivers and school personnel to work together to achieve a level of candid communication.

For many caregivers, feelings of public criticism was a key factor underpinning reported difficulties related to forming respectful and frank relationships with school and community professionals. Foster and adoptive parents alike shared experiences of feeling judged. One of the

key impacts is that many parents and caregivers remain silent and do not share their perspectives. In Chloe's opinion, "...we have to have [an] openness and...willingness to listen without being judgmental. And I think when that comes, everything else will...come too. But for right now, there are still too many people that are willing to judge..." These findings suggest that greater public awareness of FASD and the need for a new approach to engaging caregivers would contribute to a move toward a more candid and collaborative relationship between caregivers and school personnel.

Reframing Practices

The second theme to emerge was *reframing practices*. The emphasis for improved FASD awareness and understanding allows for more accurate perceptions (i.e., fewer assumptions or stereotyped beliefs), as well as greater preparation of school personnel working with this student population. Conversations centered on the subthemes of *beliefs*, *actions*, and *preparation*; in particular, how a lack of education and understanding of FASDs can lead to mistaken beliefs and perceptions, which in turn, influence the ways school personnel manage and teach affected students.

Beliefs. The subtheme of beliefs emerged solely from administrator and caregiver roles. With respect to the enrolment of students with FASDs in inclusive settings, participants in both roles relayed experiences of opposition and acceptance in dealing with school personnel. Wynne, an early education administrator, expressed feelings of relief and appreciation in detailing the addition of new students with FASDs to her school:

...for us it's a blessing...usually these little guys have trouble following directions so they're told... 'you're not listening... you're a bad kid'...so in a lot of cases...they think they're bad [but] don't really know why...So if we can catch them young enough to give them some strategies on how to remember things and follow directions, it gives them some better self-esteem...

And yet, her experiences with students with FASDs who are transitioning from one class to another suggest that not all school personnel share her sentiments: "...a teacher hears that they've got a diagnosis [and] it's like, 'maybe they shouldn't be here'...That kind of attitude we see a lot with the schools...We have a hard time getting them into classrooms...[and] educating people about these little guys..." (Wynne).

Caregivers noted similar experiences of resistance from administration and teachers when enrolling their children in school. Despite limited FASD knowledge, caregivers found school personnel still had firm beliefs about affected students' learning profiles, which were difficult to change. Mistaken beliefs or misunderstandings may be due to a lack of relevant experience, resources, or confidence. Without being able to articulate a reason, administrators and caregivers were adamant that the belief and approach of school personnel is incredibly significant in the education of students with FASDs. Participants acknowledged the need for greater understanding of the specific learning needs of affected students, in addition to the influence of attitude and approach on their educational outcomes.

Actions. Across roles, a discrepancy between knowledge and translation of that knowledge into action emerged from the analysis, with teachers having the greatest difficulty articulating appropriate classroom strategies for students with FASDs. Teacher and allied professional participants spoke to the importance of adapting educational programming to meet the specific needs of each child in a structured learning environment characterized by consistent leadership, rules, routines, and consequences for behaviour. However, when solicited to describe their strategies, the majority of participants were vague: "whatever strategy that kid needs. We have so many different strategies that we use and it's hard to pinpoint [them]...it's different depending on what you're doing" (Lisa, Teacher). Participants listed general teaching techniques that were not population-specific: "giving them...a quiet place [to work]...rewards and...things that are visual..." (Tara, Teacher), and "...establish[ing] classroom routines..." (Ella, Allied Professional). The exception was Andrea, who was able to articulate actions that, as a teacher, were effective for enhancing her

students' learning. One strategy she finds particularly useful in her FASD-specific classroom is 'thumbs up, thumbs down':

...I think ['thumbs up, thumbs down'] works so well because...our students are such strong visual learners that...all it takes is one of those...If it's pointing down...you need to fix the problem and if it's pointing up then you just keep doing what you're doing.

This example highlights knowledge as a precursor to informing practice and specific strategies tailored to students with FASDs. Although this was only one example among findings suggesting a disconnect between teachers' recognition of the individual needs of students with FASDs and the strategies they employ, it gives hope nonetheless. One of the challenges of action discussed among allied professionals was the lack of new and improved teaching strategies recommended by psychologists within the assessment report. For this role, the specificity of strategies for students with FASDs seemed to be of primary importance. School personnel may have knowledge of unique strategies but many are unsure of how to implement these in the classroom, especially with limited time, resources, and support.

Preparation. A call for improved teacher preparation and continuing education opportunities was heard clearly across all four roles. Recalling their university experiences, teachers and allied professionals reported learning little about FASD—not nearly enough for effective work with this population:

...in the teacher preparation programs there's not enough that teaches you...when I went through the teacher education program, we had one class on dealing with kids with special needs and...fetal alcohol was just a small portion of that but it is a huge portion of our reality... (Nadia, Allied Professional).

Caregivers who reported frequently meeting administrators and teachers with limited FASD understanding and experience seconded this response. Their belief is that greater post-secondary education on FASDs is key to bridging the gap between knowledge and action, and to fostering positive working relationships with families. While

administrators spoke to enhanced FASD training for pre-service school personnel, they also emphasized the importance of continuing education for teacher efficacy, as evidenced by Tom's comment: "...[we need to make] sure that people who are working with [students with FASDs]...get the professional development [they need]...to be able to recognize...these kids...without having all the information..." And yet, caregivers reported a lack of leadership among administrators in encouraging further education in this area. Although numerous professional development opportunities specific to FASD exist, caregivers noted little interest or involvement of school personnel in pursuing such training. The need for enhanced education in the area of FASD is clear. The next step is for stakeholders to make FASD training a priority and work together to engage in ongoing information-sharing about relevant materials and resources. This will allow everyone to be on the same page and remain updated about new developments in the education of affected students.

Accessing Supports

The third theme, *accessing supports*, relates to the awareness and availability of school and community supports and resources. Discussions across roles emphasized supporting students with FASDs and their families through school personnel involvement in student programming and the provision of academic and community resources to aid in healthy child development.

Awareness. Participants in all roles agreed that providing support for families of students with FASDs is an intricate process. It requires a willingness from caregivers to form relationships with school personnel and community organizations, along with public awareness of FASD and the establishment of specialized services.

School personnel and caregivers reported challenges related to finding appropriate information and support. All roles described accessing relevant information (e.g., FASD workshops, diagnostic services, and respite care) as particularly difficult; equally so was the process of connecting with educated professionals in the community. Laura, a caregiver, spoke to the difficulties she experienced in knowing

where to go and who to talk to regarding assessment and support for her grandchildren. Like many caregivers of children with FASDs, she happened upon the necessary information by chance, and it was this encounter that led to a diagnosis and access to educational resources. Without this information, Laura related that she would not have been able to advocate for her grandchildren in the way she does presently, and they would have struggled in school. The challenge of finding useful resources and support was common among caregivers, pointing to the necessity of improving information dissemination across school, healthcare, and community settings.

Availability. Participants described various experiences with resource availability, specifying greater availability of school supports than community services. School personnel expressed greater success accessing educational support (e.g., psychological services and teachers' aides) and classroom resources (e.g., FASD-specific teaching strategies and materials) than caregivers in retrieving community support (e.g., respite and leisure opportunities). Some caregivers reported being well supported in the community whereas others expressed frustration and concern about community programs and a lack of acceptance of students with FASDs.

Common across roles was the finding that resource availability diminished the more participants sought specific programs and support as students progressed through the system. Administrators expressed concern for a lack of transitional support for early learners with FASDs and the need for schools to be prepared to aid in their adjustment: "When they go to their kindergarten...that's where...things get a little tough...they're used to lots of guidance...so, it's just making sure we track where they are so we can get those supports [in place]..." (Wynne). According to school personnel and caregivers, transitional support is equally important as adolescents move into adulthood. Resources and services to help students make the transition are beginning to appear, as evidenced by Hailey, an allied professional: "...as a community we're starting to strategize around what...to [do to] meet the needs of...kids that are approaching adulthood...and we're starting to build programming around that...". However, participants highlighted the need for ongoing work in terms of understanding the

educational and social needs of students with FASDs and creating specific programs and services to meet those needs.

Discussion

The present study addresses the call for an increased presence of key stakeholders' voices in research involving students with FASDs (Duquette et al., 2006a). In particular, documenting differences and similarities across roles related to the perceptions, experiences, and aspirations of caregivers and professionals working with affected students helps to improve awareness of what is being done in our schools and what challenges remain. By imparting these differing experiences, we contribute greater understanding of stakeholders' perspectives and can begin to work toward a shared voice. The benefit of commonalities in these areas is that they allow stakeholders to work from similar frameworks with like goals for student programming and achievement, aiming to produce the best possible outcomes for students with FASDs.

Collaboration emerged across all roles as a key component for providing appropriate educative environments for students with FASDs. Participants highlighted mutual respect and candid communication as key to fostering collaborative relationships between school personnel, allied professionals, and caregivers. Teachers and caregivers who expressed difficulties in collaboration remained confident that positive working relationships are possible and that approaches taken by school personnel and caregivers play a vital role. Indeed, it is important to understand the value in each role's contribution and that all parties have a responsibility to one another and to the affected student to work together toward successful outcomes through information sharing and collaborating on program development (Timler & Olswang, 2001). To help build this relationship, it is suggested caregivers and school personnel engage in open conversations with the goal of improved understanding of their respective roles and what each stakeholder offers the collaborative process.

The fostering of positive working relationships between caregivers, school personnel, and allied professionals may help to enhance our

understanding of the learning needs of students with FASDs. In turn, this allows educators and allied professionals to form personal and professional beliefs based on accurate and sound information, as well as see where they may need more training or education to teach and plan effectively for these students. One of the main study findings highlighted that awareness of FASDs and effective teaching strategies remains limited among educational professionals. Without foundational knowledge and skill, it seems unlikely that school personnel will be able to provide appropriate programming for students with FASDs (Blackburn, 2009) or engage collaboratively with families.

Building capacity in our school personnel should begin with FASD learning at the pre-service level and also continual professional development focused on evidence-based teaching and behavior management strategies unique to this specialized population. In the current study, administrators propose that increased professional development will provide teachers with skills to better recognize affected students in the absence of diagnosis and support them in addressing specific learning needs. Dybdahl and Ryan (2009) suggest the addition of in-service programs that practically address regular classroom teachers' efforts to include students with FASDs successfully. Likewise, caregiver participants believe that it is important for special education teachers to familiarize themselves with the essential characteristics of FASDs through conference and workshop attendance and following associated research if the goal is improved learning environments for students with FASDs.

Another discrepancy needing to be addressed through improved preparation and continuing education is the incongruity between school personnel knowledge and action. Students with FASDs have specific learning challenges that may require unique strategies and resources. It is important that this knowledge is being imparted to teachers and educational assistants and that they are being given the appropriate skills and information to implement diverse strategies in the classroom and/or seek out allied professional help and community resources. It is believed that enhancing school personnel's perceptions, knowledge, and skills related to FASDs will improve their ability to collaborate with caregivers, understanding children's unique needs and removing barriers

of judgment and mistrust. One suggestion is to have mentoring opportunities wherein new school personnel can learn effective strategies from seasoned staff through classroom observations, roundtable discussions, or workshops.

The reframing of practices, as defined by changing negative attitudes and enhancing FASD knowledge and skills, is an essential component of the movement toward better educational strategies and outcomes for students with FASDs. Once the beliefs and practices of a teacher or allied professional have been reframed, he/she is in a better position to know what resources and supports will be most beneficial to meet individual student needs. All roles agreed that accessing resources could be challenging; however, the process can be even more difficult if stakeholders are lacking knowledge about appropriate resources and where to find them. Caregivers expressed considerable difficulty finding and accessing suitable supports for their children. It appears that the lack of community awareness of FASDs and anxiety in discussing the condition publicly may be reasons why resources are limited and inaccessible. An important component of advocacy then is raising awareness and establishing appropriate supports and services. Providing this information to schools, healthcare facilities, and community organizations is essential to ensuring all families of children with FASDs are well supported across home, school, and community.

Implications & Future Directions

The present study contributes to evidenced-based decision-making regarding special education policies and practices that best meet the needs of students with FASDs. The disconnect between knowledge and action can begin to be addressed through building strong relationships, enhancing understanding of effective practices, and tailoring resources to meet the unique needs of this student population. A more comprehensive understanding of an individual can be gained from the integration of multiple perspectives. Establishing respect allows for more candid conversations and an improved understanding of how school personnel and caregivers can work together responding better to the distinct patterns, needs and strengths of students with FASDs. Once

changes occur at the individual level, effective teaching strategies can be identified and educational opportunities can be built. This, in turn, will lead to innovative special education practices and more successful student outcomes. It is only when we begin to understand effective techniques that we can adequately prepare our teachers and make better decisions about necessary supports and resource allocation.

Our discussion with stakeholders involved in the education of students with FASDs has only just begun. This first phase of research demonstrates the importance of talking to key stakeholders and fostering communication and collaboration between home and school. The barriers to positive working relationships revealed provide a starting point for researchers and special education professionals seeking to improve practice and affect change. To this end, it will be important to consider the following questions: (a) what constitutes effective collaboration and how do we facilitate the development of positive working relationships between families and school personnel?; (b) how can we better educate and train school personnel in teaching students with FASDs and enhance awareness of this condition within the community?; and (c) what programs and services will best support students with FASDs and their families and how do we go about implementing them? Research and practice concentrated on these questions will undoubtedly enhance our understanding of the collaborative process as it pertains to the improvement of supports and educational programming for students with FASDs with the end goal of successful academic, social, and behavioral outcomes.

Notes

Contributors and Supporting Agencies: Edmonton Public School Board; Alberta Centre for Child, Family, & Community Research

References

- Blackburn, C. (2009). *FASD building bridges with understanding: The acquisition of practitioner knowledge in relation to the management of support of children with Foetal Alcohol Syndrome and related disorders*. Retrieved from http://www.sunfield.org.uk/pdf/FASD_Building_Bridges.pdf
- Blackburn, C., Carpenter, B., & Egerton, J. (2010). Shaping the future for children with foetal alcohol spectrum disorders. *British Journal of Learning Support*, 25(3), 139-145. doi: 10.1111/j.1467-9604.2010.01452.x
- Blackburn, C., Carpenter, B., & Egerton, J. (2009). *Facing the challenge and shaping the future for primary and secondary aged students with Foetal Alcohol Spectrum Disorders (FAS-eD Project)*. London, England: National Organisation on Fetal Alcohol Syndrome-UK.
- Brown, J. D. (2004). Family supports for children who have alcohol-related disabilities. *Developmental Disabilities Bulletin*, 32(1), 44-61.
- Burd, L., Klug, M. G., Martsof, J. T., & Kerbeshian, J. (2003). Fetal alcohol syndrome: Neuropsychiatric phenomics. *Neurotoxicology & Teratology*, 25, 697-705. doi 10.1016/j.ntt.2003.07.014
- Carpenter, B. (2011). Pedagogically bereft: Improving learning outcomes for children with Foetal Alcohol Spectrum Disorders. *British Journal of Special Education*, 38(1), 37-43. doi: 10.1111/j.1467-8578.2011.00495.x
- Chudley, A. E., Conry, J., Cook, J. L., Looock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *CMAJ*, 172, 1-21. doi: 10.1503/cmaj.1040302
- Connor, P., & Streissguth, A. (1996). Effects of prenatal exposure to alcohol across the lifespan. *Alcohol Health Research*, 20, 148-157.
- Creswell, J. W. (2012). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (4th edition). Boston, MA: Pearson.

- Duquette, C., Stodel, C., Fullarton, S., & Hagglund, K. (2007). Secondary school experiences of individuals with fetal alcohol spectrum disorder: Perspectives of parents and their children. *International Journal of Inclusive Education*, 11(5-6), 571-591. doi: 10.1080/13603110600668611
- Duquette, C., Stodel, E., Fullarton, S., & Hagglund, K. (2006a). Persistence in high school: Experiences of adolescents and young adults with Fetal Alcohol Spectrum Disorder. *Journal of Intellectual & Developmental Disability*, 31(4), 219-231. doi: 10.1080/13668250601031930
- Duquette, C., Stodel, E., Fullarton, S., & Hagglund, K. (2006b). Teaching students with developmental disabilities: Tips from teens and young adults with fetal alcohol spectrum disorder. *Teaching Exceptional Children*, 39(2), 28-31.
- Dybdahl, C. S., & Ryan, S. (2009). Inclusion for students with fetal alcohol syndrome: Classroom teachers talk about practice. *Preventing School Failure*, 53(3), 185-195.
- Green, J. H. (2007). Fetal alcohol spectrum disorder: Understanding the effects of prenatal alcohol exposure and supporting students. *Journal of School Health*, 77(3), 103-108. doi: 10.1111/j.1746-1561.2007.00178.x
- Health Canada. (2006). *It's your health: Fetal alcohol spectrum disorder*. Retrieved March 15, 2011 from <http://www.hc-sc.gc.ca/hl-vs/iyh-vsv/diseases-maladies/fasd-etcaf-eng.php>
- Kelly, S. J., Day, N., & Streissguth, A. P. (2000). Effects of prenatal alcohol exposure on social behaviour in humans and other species. *Neurotoxicology and Teratology*, 22, 143-149.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.
- McCarty, C., Waterman, J., Burge, D., & Edelstein, S. B. (1999). Experiences, concerns, and service needs of families adopting children with prenatal substance exposure: Summary and recommendations. *Child Welfare*, 78(5), 561-577.
- Mellard, D., & Lancaster, P. (2003). Incorporating adult community services in students' transition planning. *Remedial and Special Education*, 24(6), 359-368. doi: 10.1177/07419325030240060701

- Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Jossey-Bass.
- National Organization on Fetal Alcohol Syndrome—South Dakota (NOFAS-SD). (2009). *Fetal Alcohol Spectrum Disorders education strategies in the education system*. Sioux Falls, SD: Center for Disabilities, Sanford School of Medicine, University of South Dakota.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3d ed.). Thousand Oaks, CA: Sage Publications.
- Pei, J., Job, J., Poth, C., O'Brien-Langer, A., & Tang, W. (2012). *Teaching students with Fetal Alcohol Spectrum Disorders: Knowledge and beliefs of pre-service teachers*. Unpublished manuscript.
- Pei, J., Denys, K., Hughes, J., & Rasmussen, C. (2011). Mental health issues in fetal alcohol spectrum disorder. *Journal of Mental Health, 20*(5), 438-448. doi: 10.3109/09638237.2011.577113
- Purdey, C. D. (2006). *Children diagnosed with fetal alcohol spectrum disorder: A student-based needs assessment*. Retrieved from <http://dtpir.lib.athabascau.ca/action/download.php?filename=caap-loi/Charleen%20Purdey%20Letter.pdf.pdf>
- Rasmussen, C. (2005). Executive functioning and working memory in Fetal Alcohol Spectrum Disorder. *Alcoholism: Clinical and Experimental Research, 29*, 1359-1367.
- Rasmussen, C., Andrew, G., Zwaigenbaum, L., & Tough, S. (2008). Neurobehavioural outcomes of children with fetal alcohol spectrum disorders: A Canadian perspective. *Pediatric Child Health, 13*(3), 185-191.
- Ryan, S., & Ferguson, D. L. (2006a). On, yet under, the radar: Students with fetal alcohol syndrome disorder. *Exceptional Children, 72*(3), 363-365.
- Ryan, S., & Ferguson, D. L. (2006b). The person behind the face of fetal alcohol spectrum disorder: Student experiences and family and professionals' perspectives on FASD. *Rural Special Education Quarterly, 25*(1), 32-40.
- Streissguth, A. (1997). *Fetal Alcohol Syndrome: A guide for families and communities*. Baltimore, MD: Paul H. Brooks.

- Streissguth, A. P., Aase, J., Clarren, S., Randels, S., LaDue, R., & Smith, D. (1991). Fetal alcohol syndrome in adolescents and adults. *Journal of the American Medical Association*, 265(15), 1961-1967.
- Streissguth, A. P., Sampson, P. D., Olson, H. C., Bookstein, F. L., Barr, H. M., Scott, M., Feldman, J., & Mirsky, A. F. (1994). Maternal drinking during pregnancy: Attention and short-term memory in 14-year-old offspring—A longitudinal prospective study. *Alcoholism: Clinical & Experimental Research*, 18, 202-218.
- Timler, G. R., & Olswang, L. B. (2001). Variable structure/variable performance: Parent and teacher perspectives on a school-age child with. *Journal of Positive Behavioral Interventions*, 3(1), 48-56.
- Williams, R. J. (1999). The role of psychological tests in FAS/E. In J. Turpin & G. Schmidt (Eds.), *Fetal Alcohol Syndrome/Effect: Developing a community response* (pp. 44-55). Halifax, NS: Fernwood.

Jenelle Marie Job is Doctoral Candidate in the School Psychology, University of Alberta, Canada.

Cheryl Anne Poth is Assistant Professor of Measurement, Cognition & Evaluation in the Department of Educational Psychology, University of Alberta, Canada.

Jacqueline Pei is Assistant Professor of School Psychology in the Department of Educational Psychology, University of Alberta, Canada.

Belina Caissie is Assistive Technology for Learning Consultant with Edmonton Regional Educational Consulting Services, Canada.

Deborah Brandell is Supervisor for Special Education at the Edmonton Public School Board, Canada.

John Macnab is Program Coordinator for Research Support Services at the Edmonton Public School Board, Canada.

Contact Address: 6-102 Education North, University of Alberta, Edmonton, Alberta, Canada T6G 2G5. Email: job@ualberta.ca