Vehicles for Change: Conversation and Collaboration in Support of Children with Fetal Alcohol Spectrum Disorders

By

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ABSTRACT

Fetal Alcohol Spectrum Disorder (FASD) constitutes a highly complex and controversial public health concern among researchers, practitioners, policymakers, and public citizens and can lead to devastating cognitive, physical, and functional impairments (Chudley et al., 2005; Streissguth & O'Malley, 2000). Caused by maternal consumption of alcohol during pregnancy, this preventable developmental disability damages the brain and central nervous system in critical and lasting ways. The permanency of the condition creates serious educational, social, and societal implications, as those affected often require lifelong support and resources (Ospina & Dennett, 2013; Streissguth et al., 1994). Increased scientific and practical knowledge are necessary for the advancement of targeted supports and the establishment of effective evidence-based interventions (Gould, Job, St. Arnault, Pei, & Poth, 2012).

To that end, 5 published manuscripts comprise this dissertation, reporting data from 2 large-scale research studies focused on FASD service delivery in Alberta, Canada (Poth & Pei, 2012). A multi-methods research design rooted in phenomenology and thematic analysis is presented as an appropriate and trustworthy means of accessing stakeholder experiences, highlighting current FASD program and service strengths and weaknesses. One hundred and seven participants serving affected children across 5 roles and 3 settings emphasized the necessity of collaboration and communication and detailed barriers to the development of positive working relationships and effective agency within each service domain: *prevention*, *assessment*, and *intervention*. This dissertation contributes to the academic literature elements of a collaborative, intentional, and reflective service delivery approach that has the strong potential for informing future policy, strategic planning, and programming. Practical implications specific to the education, care, and advocacy of children and families affected by FASD are discussed.

PREFACE

The published research included in Chapter 3 of this dissertation is part of two large-scale studies composed of 10 individual projects. Research ethics approval for 2 of these projects cover the research in this dissertation: 1. Project name: "*Enhancing the assessment process*," Pro00004181, December 29, 2008 and 2. Project name: "*An Evaluation of the Alberta Parent Child Assistance Programs*," Pro00028475, February 3, 2012. Research collaborations were led by Drs. Jacqueline Pei and Cheryl-Anne Poth at the University of Alberta and completed with members of the Edmonton Public School Board (Project 1) and the Parent and Child Assistance Program in conjunction with the Government of Alberta (Project 2). Project 1 led to the publication of the following 3 articles:

1. Pei, J., Job, J. M., Poth, C., & Atkinson, E. (2013). Assessment for intervention of students with fetal alcohol spectrum disorders: Perspectives of classroom teachers, administrators, caregivers, and allied professionals. *Psychology, 4*(3A), 325-334. doi: 10.4236/psych.2013.43A047
2. 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
3. Poth, C., Pei, J., Job, J. M., & Wyper, K. (2014). Toward intentional, reflective, and assimilative classroom practices with students with FASD. *The Teacher Educator, 49*(4), 247-264. doi: 10.1080/08878730.2014.933642

The second collaboration with the Parent and Child Assistance Program and the Government of Alberta resulted in the publication of the following 2 manuscripts:

1. Job, J. M., Poth, C-A., Pei, J., Wyper, K., O'Riordan, T., & Taylor, L. (2014). Combining visual methods with focus groups: An innovative approach for capturing the multifaceted and complex work experiences of Fetal Alcohol Spectrum Disorder prevention specialists. *International Journal of Alcohol and Drug Research, 3*(1), 71-80. doi: http://dx.doi.org/10.7895/ijadr.v3i1.129
2. Atkinson, E., Job, J., Pei, J., Poth, C., O'Riordan, T., & Taylor, L. (2013). Capturing the experiences of FASD prevention workers through quilting. *First Peoples Child & Family Review, 8*(1), 122-129.

Taking a collaborative, team approach to process and publication, Drs. Pei and Poth allowed me to take a coordinator role for scheduling, data collection, transcription, interpretation, and analysis, leading a team of research assistants and providing secondary supervision on focus group facilitation, transcription, code and theme development, and summary writing. This model also endorsed equal opporunity to primary authorship, rotating author position across manuscripts. Regardless of author position, my contribution to the literature review, data analysis and interpretation, discussion, and edits remained high for all articles, and I was responsible for submission and revision on the 2 manuscripts on which I am first author.

DEDICATION

This dissertation is dedicated in loving memory to my grandmother, **Antonie Ternes**. Her life was a true testament to the strength of the human spirit and our ability to overcome despite insuperable odds. With resolute determination, careful courage, and unwavering faith, my Grandma escaped the Nazi regime during WWII and sailed to a new life in Canada. Never once did I hear her complain or curse. She was too busy being thankful for all the blessings bestowed her family. Her quiet humility spoke volumes as she loved, shared and encouraged for the sincere joy of giving to another without want or expectation. If ever I were to see Jesus in another, it would be my Grandma Tonie.

She may not have known it but my Grandma sowed seeds far beyond her beloved raspberries, blueberries, peas, and carrots—seeds of diligence, patience, perseverance, dedication, and hope. She worked tirelessly and sacrificed much for the betterment of her family. It is my supreme privilege to have been her granddaughter and my honor to submit this dissertation as fruit for her labor of love. Grandma, I will love you always and miss you greatly. You are my hero.

"The deeper the dark, the closer the dawn. However profound the suffering
that envelops you; never forget the inner spark of hope and courage.
Never lose the capacity to wait with patient enduring."

Daisaku Ikeda

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Today, I give thanks to everyone who has been a part of my doctoral journey. It has been a long road indeed with more bumps and obstacles than I care to remember. Many days, I didn’t know if I’d make it; if I had the fortitude to reach the end. It was at these times that your voices sang in beautiful unison, encouraging me to keep looking up, take another step forward, write one more line and finish what **WE** started…It is to each of you that I owe my deepest gratitude.

First and foremost, I must thank my loving savior, **Jesus Christ**. I would be foolish to think that anything in my life comes solely by way of personal effort and determination. I have experienced too many miracles to believe that God’s grace is not the driving force behind all of my endeavors and successes. It makes me proud to be able to give glory to Him through this work and say thank you for never leaving me to walk (or write) alone.

Next, there is my family—a crazy bunch of personalities, ideas, and emotions. I love you guys more than I can say, and I thank you for sticking with me through the ups and downs of this seemingly endless journey. **Dad and Mom**, your countless phone calls inquiring about my progress drove me bananas but ultimately, kept my focus on the prize. Mommy, pack your bags and get a fist full of “Dad’s” money because Italy is calling our names! And in case you didn’t already know, the “grazies” are all you. For all the times you feel you failed us, please know that I only remember the rising up, dusting off, and moving forward. Never once have I questioned your love for your children, your faith in God’s provisions, and your commitment to one another. You are people of integrity—loyal and dependable friends, generous and compassionate servants, bold and resolute leaders. The strength of your character is the backbone of your success and the reason why your sons and daughter have such loving and fighting spirits.
Thank you for your guidance, backing, and example. I am so very proud to be your daughter.

To **Paul, Matthew, Erika, and Samantha**, I couldn't have asked for better brothers and sisters. They don't tell you when you start that completing a doctoral degree is two parts hard work and perseverance and about a thousand parts managing the rest of life's curve balls. You each stepped up to the plate with me, and were there when I needed you most...PJ through the 3 wise phone conversations you did not screen out and Matty through the hours of writing on that jenky moon-and-star lap desk you bought me for Christmas 2001 🤗. I may be your big sister but I look up to you with pride and admiration. Next, there's my **Nana, Wilma Yanor,** who asked me to hurry up and finish this darn dissertation before she died so she could brag to her friends at Bridge Club. Well, Nan, the time has come and you're still kicking, so get your boast on! I am also fortunate to have an amazing extended family in my corner to cheer me up and cheer me on—**Auntie Louise and Uncle Ed**, **Uncle Wayne, Auntie Gretel, and my cousins: Tim and Shelley, Aaron, Noelle, Eli, and Anson, Sarah, Jim and Jodie, Pat, Chantelle and Nicholas, Brandon, Sheldon, Shannon, and Nathan, Liese, Justin and Stephen.** The love of my family has always been a constant light in my life even through the darkest of times. When one of us hurts, we all hurt and when one of us succeeds, we all succeed. Your pride in my accomplishment makes me smile so big but truly this achievement is as much yours as it is mine. Although, let's not get carried away calling all ourselves "doctor" this year. HA!

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To all my amazing friends/sounding boards/shoulders to cry on who have contributed so richly to my life, especially **Stephie, Kirstyn, Kiki, Ian, Jenny, Julie, Reanna, Michelle, Jen, Martha, Jenn, Ty, Abel, Carol, Mar, Annie, Eric, Ashley, Brian and Chinnu**. I am sending an endless stream of **XO**s. You each hold a special place in my heart, and I wish you nothing but happiness and love all your lives.

And who could forget my ragamuffin fur babies, **Jasper and Jax**? Running straight from the mean streets of Dallas and into my heart, you two are the worst tramps ever but the best gifts I could've received. We were meant to be, us three. Now if only you could understand the importance of sleeping in on Saturday…

It is with sincere gratitude that I acknowledge my doctoral supervisors, **Drs. George Buck and Robert Klassen**. Dr. Klassen guided me through successful completion of my Master's degree and the beginning stages of my doctorate. He provided me with opportunities to advance my research skills and spent many hours discussing ideas, results, and manuscripts. His counsel and encouragement gave me confidence in my work and desire to push myself toward new endeavors. Despite his many academic and professional commitments, Dr. Buck always makes time for his students and works hard to ensure their voices are heard. When Dr. Klassen was no longer able to supervise me, Dr. Buck readily stepped in and said, "let's get this done!" He supervised with wisdom and care, greatly committed to helping me put forth a dissertation I could be proud of and ensuring tremendous learning and growth along the way. George, your passion, wisdom, kindness, and dedication are inspiring and noteworthy. I only hope that one day I will be able to offer my students even a tenth of the support and confidence you afforded me.

I would also like to recognize the efforts of the members of my doctoral committee, **Drs. Jacqueline Pei, Henry Janzen, Christina Rinaldi, Veronica Smith, and Jennifer Green** who spent countless hours reading my dissertation, challenged me to think critically about my work, and provided brilliant analysis and feedback.

Additionally, it makes me very happy to express my thanks to the principal investigators with whom I worked throughout my doctoral journey, **Drs. Jacqueline Pei, Cheryl-Anne Poth, and Carmen Rasmussen**. Your enthusiasm, drive and commitment to the amelioration of FASD awareness, prevention, assessment and intervention programs through research and publication are commendable. It was a privilege and pleasure to learn from you and I thank you for the opportunity to be a part of your teams including the Alberta Clinical and Community-based Evaluation Research Team (ACCERT) and the UAlberta FASD Research Group. I miss my research families immensely.

Finally to the **families, school personnel, frontline workers, researchers, community agencies, funding organizations and government officials who care for children and adults living with FASDs** and work hard to bring about improved understanding, supports and resources, you are the true heroes of this book and the ultimate reason for completion. Your stories are of the utmost importance and it has been my honor to listen and share your words.

With simple brilliance, Ralph Waldo Emerson once said, "*the reward of a thing well done is to have done it.*" Well y'all, **WE DID IT** and the victory tastes sweeter than honey!

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CHAPTER I

INTRODUCTION

"…we have to have [an] openness and…willingness to listen without being judgmental.
And I think when that comes, everything else will come too…"
Chloe, caregiver of a child with an FASD

This dissertation is a collection of completed qualitative studies exploring the current state of Fetal Alcohol Spectrum Disorder (FASD) prevention, assessment, education, programming, and service delivery in Alberta, Canada according to frontline workers, caregivers, teachers, administrators, and allied professionals involved in the care and advocacy of children and families affected by FASD. Due to the complex and sensitive nature of FASD, many related programs and services are in their infancy in both development and scope. Increased scientific and practical knowledge are necessary building blocks then for the advancement of FASD supports and resources and establishment of effective evidence-based interventions (Gould, Job, St. Arnault, Pei, & Poth, 2012).

Background and Context

FASD constitutes an international public health concern with serious educational, social and societal implications as those affected suffer permanent deficits, necessitating lifelong care and support (Chudley et al., 2005; Ospina & Dennett, 2013; Streissguth et al., 1994). Maternal consumption of alcohol during pregnancy is the leading known cause of preventable developmental disability in the world, and can lead to critical mental and physical birth defects including prenatal and/or postnatal growth retardation, facial dysmorphology, mental retardation and functional deficits, and central nervous system dysfunction (Burd et al., 2003; Chudley et al., 2005; Coles et al., 1991; Kodituwakku, 2007; Streissguth et al., 2004). Establishing the prevalence of FASD in the general population has proved an intricate task due to the sensitive and complex nature of the disorder. Estimates of prevalence range from 0.2 to 3 out of every 1000 live births for fetal alcohol syndrome (FAS) (May & Gossage, 2001; Stratton, Howe & Battaglia, 1996) and 1 to 5% of children for the full continuum of FASDs (Health Canada, 2006; May et al., 2014; May et al., 2009; Sampson et al., 1997; Stade, Ungar, Stevens, Beyen, & Koren, 2007). And yet, these rates paint only a partial picture of those affected as diagnosis of the condition is challenging and involved, and may be delayed or missed entirely (Sokol, Delaney-Black, & Nordstrom, 2003).

The harm incurred to an unborn child by prenatal alcohol exposure (PAE) may not be evident at birth but materialize as the brain and body develop and mature (Wollard, 2012). Alcohol is a teratogen that passes easily from mother to child through the placenta with little way to eliminate it. This exposes the developing fetus to a higher concentration of alcohol for a longer period of time, leading to deleterious effects (Ben-Joseph, 2013; Streissguth & O’Malley, 2000). Indeed, “of all the substances of abuse—including heroin, cocaine and marijuana—alcohol produces by far the most serious neurobehavioral effects in the fetus” (Stratton et al., 1996, p. 35). FASDs can cause a slow growth rate, failure to thrive, problems with coordination, and significant functional problems in cognition and behavior (e.g., cognitive delay, poor executive function and lack of inhibition, inattention and hyperactivity, specific learning difficulties, immaturity and credulity, limited social awareness and difficulty applying knowledge to new situations (Burd, Klug, Martsolf, & Kerbeshian, 2003; Center for Disease Control and Prevention [CDC], 2014b; Chudley et al., 2005; Connor & Streissguth, 1996; Kelly, Day, & Streissguth, 2000; Pei, Denys, Hughes, & Rasmussen, 2011; Rasmussen, 2005). Abstaining from alcohol during pregnancy is the only way to prevent these disabilities with total assurance (American Academy of Pediatrics [AAP], 2012).

Statement of the Problem

Recognizing that FASD is preventable must come with the understanding that it is a multifaceted and complicated social and public health concern involving numerous systems of care including healthcare, education, criminal justice, child welfare, and social services (Job et al., 2014). Effective treatment and management of FASD-related disabilities requires costly, comprehensive and ongoing supports and resources. It is estimated that the lifetime cost of care for an individual with an FASD is between $1.14 and $2 million dollars (Lupton & Harwood, 2004; Popova, Stade, Bekmuradov, Lange, & Rehm, 2011; Stade et al., 2009) with funds needed for neonatal care, developmental disability services, special education, drug and alcohol abuse treatment, mental health care, and supported living. However, not all affected persons receive the multidisciplinary support and programming they need to be successful, leading many to experience devastating secondary disabilities (e.g., mental health issues, disrupted school experience and/or dropout, substance abuse, trouble with the law and confinement, unemployment, sexual inappropriateness, and dependent living (Popova, Stade, Lange, Bekmuradov, & Rehm, 2012; Streissguth, Barr, Kogan, & Bookstein, 1996). The social and economic impacts of FASDs are substantial, and lend themselves well to conversation about the benefits of research in prevention, assessment, and intervention, centering on understanding *who* is at risk and *why* services are required (awareness and prevention), *what* areas and domains are affected (assessment), and *how* needs and concerns of affected individuals can best be addressed (intervention) (Job et al., 2014; Poth & Pei, 2012).

Significance of the Research

The research presented in this dissertation are part of a larger examination of FASD service delivery particularly as it relates to assessment and diagnosis, teacher preparation and educational practices, and school- and community-based interventions (see Job et al., 2013; Pei, Job, Poth, O'Brien-Langer, & Tang, 2015; Poth & Pei, 2012; Poth, Pei, Job, & Wyper, 2013). These studies address the call for increasing the voice of school personnel, caregivers, and allied professionals (e.g., counselors, prevention specialists, social workers) in FASD research and development of supportive interventions (Dybdahl & Ryan, 2009; Gearing, McNeill, & Lozier, 2005; Rutman, 2013; Streissguth, 1997). To this end, key stakeholders across projects emphasized the necessity of collaboration and communication between individuals invested in the care of children with FASDs, and detailed barriers to the development of positive working relationships and effective intervention within each service domain: ***prevention***, ***assessment***, and ***intervention***. Manuscripts one and two report the experiences of FASD prevention specialists working with affected and at-risk women and children, and contribute to the literature in 3 important ways: 1) visual methods are introduced as a unique and evocative approach to data collection; 2) individual and collective stories are central to the collaborative process and enhance participants' connection to the research; and 3) researcher impact is included as an expression of validation and gratitude—listening to *understand* rather than to reply.

Manuscripts three through five shift focus to assessment and intervention, providing a comprehensive look at the educational impact of FASD from multiple perspectives. The school setting offers a unique space to observe the distinct set of challenges experienced by students with FASDs (Green, 2007) and readily highlights developmental and behavioral differences in relation to their same age peers. Therefore, individuals who work closely with students in this context possess valuable information useful for evaluation, educational programming, behavioral intervention, and social-emotional learning. It is well recognized that efforts directed at increasing educator knowledge, preparation, and collaboration are paramount to producing the best possible outcomes for students with FASDs (Blackburn et al., 2010; McCarty et al., 1999; Streissguth, 1997); yet, no study has explored how these elements interact in practice. It is put forth that discussion with key players involved in the education and support of affected students will bring about greater awareness of the collaborative efforts of teachers, administrators, caregivers, and allied professionals (e.g., counselors, social workers) to understand and surmount the developmental, learning, and behavioral challenges of students with FASDs. The importance of these manuscripts for advancement of research in the field centers on 4 main ideas: 1) conversations with individuals in various roles allow for a more informed view of stakeholder knowledge, assessment and instructional practices, and areas of weakness in education and intervention; 2) caregivers and allied professionals provide important information about the interaction of school, home, and community systems; 3) the integration of differing perspectives lends itself well to a holistic guiding framework for teaching and intervention, emphasizing the *whole child*; and 4) best practices in collaboration, communication, and intentional and reflective practice.

FASD has often been referred to as the ‘invisible disability’ due to a lack of observable, external physical signs in many cases (Malbin, 2004) but hopefully not for long. School personnel and allied professionals are in a unique position to identify and effectively address the specialized needs of students with FASDs when adequately educated and prepared for their presence in the classroom (Millar et al., 2014). Additionally, schools are well positioned to amend secondary disabilities and decrease stigma by helping affected students understand their individual learning profiles, teaching and modeling needed skills (e.g., cause-and-effect learning), and encouraging strengths and talents to support education and employment goals, relationships, and special interests (Millar et al., 2014). It is for these reasons that the conversations documented in this dissertation are so important; they are sincere, relatable, and encouraged: “Conversation is the vehicle for change. We test our ideas. We hear our own voice in concert with another. And inside those pauses of listening, we approach new territories of thought…” (Williams, 2012, ch. XV).

Theoretical Framework

A qualitative research design rooted in phenomenology and thematic analysis was selected as appropriate for generating rich descriptions of stakeholder experiences involved in the education and care of students with FASDs. The purpose of qualitative phenomenological research is to describe a ‘lived experience,’ which befits the objectives of the studies contained in this dissertation. The choice of focus groups and interviews as suitable methods of data collection was based on the desire for facilitated discussions around experiences of working with students with FASD (Krueger & Casey, 2000). A semi-structured format was employed to guide conversation, allowing thoughts, feelings, and memories to flow naturally rather than directing descriptions of experiences (Waters, 2013). A distinct advantage of a focus group or interview is their effectiveness in collecting rich qualitative data in a short amount of time—observing the interactions among participants and providing opportunities for participants to connect with and further the responses of others (Creswell, 2009). Trustworthiness and confidence in the data was established through the use of verbatim transcripts, member checking, and multiple researchers for code and category assignment (Merriam, 2009; Patton, 2002). Focus groups and interviews were used in all studies whereas the addition of a visual method (i.e., quilting) was only used with prevention specialists. The incorporation of aesthetic expressions (i.e., creating an artistic representation of participant experience on quilting blocks) provided researchers insight into how participants’ work affects them on a personal level. The use of visual methods for documenting and representing the social world has resulted in improved understanding of participant experiences and relationships in research (Banks, 2001; Pink, 2007; Rose, 2001).

Consistent with phenomenological and thematic analysis approaches, data analysis followed an *emergent* process—allowing meaning to emerge from the data. The process of understanding the essential meaning of the experiences was to abstract out themes through first identifying common words and topics, assigning codes, and grouping together like codes into categories. The thematic analysis occurred after the coding and categorization processes as researchers aggregated similar content to form major themes and concepts. These are the essential features of the narrative "without which the experience would not have been the same" (Waters, 2013, para. 4). Thematic analysis guided interpretation, bringing together the individual encounter to form a collective experience (Braun & Clarke, 2006). After codes had been assigned to transcript data, content analysis and constant comparison were employed to eliminate redundant codes within transcripts and amalgamate similarly coded conversation across transcripts. An analogous approach was used with quilting blocks, albeit through interpretation of elements specific to visual representations (e.g., lines, colors, images, flow, and valence). Researchers engaged in a process of reflection used to determine the meaning of the art on each quilting block, and what elements were 'essential' to the piece (Waters, 2013). While a constant comparison approach is inherent in grounded theory methodology, many other methodologies employ this analytic strategy to enhance the descriptive and interpretive quality of the data, and create knowledge about common patterns and themes within human experience. It is for this reason that thematic analysis is often used in tandem with a constant comparison approach where the goal is to "tak[e] one piece of data (one interview, one statement, one *theme*) and compar[e] it with all others that may be similar or different in order to develop conceptualizations of the possible relations between various pieces of data" (Thorne, 2000, p. 2).

Research Objectives

This dissertation serves to increase the links between research and practice in supporting the development of FASD programs and services that effectively address the needs and abilities of individuals with FASDs. Specifically, the following five objectives are put forth:

(a) Provide an overview of the disorder and associated health, social, and educational implications;

(b) Review relevant research to generate shared understandings related to best practice in FASD prevention, assessment, and intervention;

(c) Document the experiences of key stakeholders in the planning and delivery of FASD programs and services using a variety of methodological approaches;

(d) Contribute to the academic literature features of a collaborative planning and service delivery approach and evidence-based practice that lead to positive outcomes for service providers and recipients; and

(e) Highlight key areas to direct future research and practice in the field.

Chapter Summaries

This dissertation consists of 5 chapters. Chapter one comprises a brief introduction to the prevalence of Fetal Alcohol Spectrum Disorders and the social, educational, and societal implications associated with the condition. This chapter also presents rationale for the research including a statement of the problem, study objectives, guiding theoretical frameworks, and significance for dissemination. Chapter two provides an overview of the studies compiled with summaries of the key components (i.e., participants, methodology, data collection and analyses, and aassumptions and limitations) of each manuscript to allow for quick reference in review.

Chapter three is composed of the five manuscripts formatted from their published state to match this dissertation and organized according to their relevancy to one of three major areas of research in the field: prevention, assessment, and intervention. Reference lists were removed from the end of each manuscript to enhance readability and flow of ideas, and merged to form a single reference section after the final chapter. Chapter four summarizes the dissertation and allows for a cohesive, connected discussion of the manuscripts in terms of their significance to each other and importance as a collected work. Chapter five outlines the implications of this research and proposes a systematic model for collaborative planning and integrated service delivery in the care of children with FASDs. Chapter six is comprised of concluding remarks, lessons learned, and directions for the development of future programs of research and intervention. An overall reference section, list of tables and figures, and appendices accompanies the core document.

Glossary of Terms

Fetal alcohol spectrum disorders (FASD) is a non-diagnostic umbrella term that describes the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects can be physical, mental, or behavioral, with possible lifelong implications.

Four diagnoses fall under the umbrella of FASD:

- ***Fetal alcohol syndrome (FAS)*** is the most severe form of FASD, and consists of a pattern of neurological, behavioral, and cognitive deficits that can interfere with growth, learning, and socialization. Persons with full FAS display facial abnormalities (e.g., smooth philtrum, small eye openings, thin upper lip), growth deficiencies (e.g., low birth weight), and central nervous system damage (i.e., structural, neurological, and/or functional impairment).

- ***Partial fetal alcohol syndrome (pFAS)*** describes persons with confirmed alcohol exposure, facial anomalies, and one other group of symptoms (i.e., growth retardation, central nervous system defects, or cognitive deficits).
- ***Alcohol-related neurodevelopmental disorders (ARND)*** refer to various neurological abnormalities such as problems with communication, attention and impulsivity, memory, learning ability, visuospatial skills, intelligence, and motor coordination. Children with ARND have central nervous system deficits but not all the physical features of FAS.
- ***Alcohol-related birth defects (ARBD)*** describe defects in the skeletal and major organ systems. They may include abnormalities of the heart, eyes, ears, kidneys, and skeleton, such as holes in the heart, underdeveloped kidneys, and fused bones.

Prenatal alcohol exposure (PAE) refers to the alcohol exposure a developing fetus experiences in utero due to maternal drinking during pregnancy.

Primary disabilities are deficits that reflect most directly the underlying brain and central nervous system damage caused by prenatal exposure to alcohol (e.g., mental retardation).

Secondary disabilities are those that an individual is not born with, and could presumably be ameliorated through better understanding and appropriate interventions (e.g., substance abuse).

FASD-informed describes an approach to care and education that considers the child with an FASD across settings, understanding that he/she may be affected in a variety of ways (e.g., cognitively, socially, emotionally, or spiritually). Therefore, to benefit from programs and services, adaptations must be made to meet the unique needs of the affected child and foster individual strengths.

Qualitative inquiry uses an inductive and holistic approach to understand the phenomena of interest, exploring the depth, richness, and complexity of variable interactions. Some examples of qualitative design include grounded theory, phenomenology, case study, ethnography, and content analysis.

Visual research is a qualitative research methodology that relies on the use of artistic mediums (e.g., film, photography, sculpture, drawing and painting) to produce and represent knowledge and reality.

Multimethodology includes the use of more than one method of data collection or research in study or set of related studies (e.g., quilting blocks and focus groups).

Phenomenological research attempts to understand the essence of a phenomenon by examining the views of individuals who have experienced that phenomenon.

Thematic analysis is a common analytical technique in qualitative research. It serves to identify, organize, and report patterns or *themes* within the collected data, allowing for rich description of the data set.

Constant comparative analysis requires the researcher to take a piece of data and compare it to all other pieces of data to determine similarities and differences.

Valence refers to the emotional tone of an event, object or situation. For example, the emotions generally characterized as ‘negative’ such as anger and fear could be described as having a negative valence.

CHAPTER II

OVERVIEW

Five published manuscripts comprise this dissertation, reporting data from two large-scale research studies using quantitative, qualitative, and multi-method approaches. Studies were geared at improving our understanding of current issues in FASD ***prevention***, ***assessment***, and ***intervention*** and providing direction for future research and practice. Findings have been presented at regional, national, and international conferences including but not limited to the Second European Conference on Education in Barcelona, Spain (October 2012), the Eighth International Congress of Qualitative Inquiry in Chicago, Illinois (May 2012), the Hawaii International Conference on Education in Honolulu, Hawaii (January 2011), the Alberta FASD Conference in Calgary, Alberta (February 2010), and the Glenrose Rehabilitation Hospital Spotlight on Research in Edmonton, Alberta (November 2009). An overview of each article is presented through synopsis of the study's contents, methodology, and contributions to the literature.

From 2009 to 2012, I served as project coordinator for the Alberta Clinical and Community-based Evaluation Research Team (ACCERT). My involvement extended from planning to publication, allowing for growth in qualitative and multi-methods research and leadership in mentoring and training research assistants in data collection, transcription, coding and thematic analysis, and qualitative writing. Our collaborative approach to publication allowed lead researchers equal opporunity to primary authorship, rotating author position across manuscripts. My contribution to the literature review, data analysis and interpretation, discussion, edits, and submission process remained high for all articles regardless of author position. Furthermore, I held a lead role in focus group facilitation, transcription, code and theme development, and summary writing across projects, which gives me confidence in my familiarity with the data and understanding of the findings and implications.

Prevention

Two papers describe the usefulness of a multi-methods approach to FASD research, combining visual and focus group mediums. This novel approach was especially relevant for prevention specialists involved in the *Parent and Child Assistance Program (PCAP),* a program dedicated to the support of women at-risk of alcohol-exposed pregnancies. Staff had frequently been recruited for research and program reviews where the process was onerous and the results were of limited value. Design of quilting pieces allowed PCAP workers to share their personal and professional experiences in an innovative and creative way, and assembly of the quilting pieces facilitated the integration of participants' stories into a meaningful collective experience (Koelsch, 2008). Focus group discussions allowed for more directed conversation related to research use, training, and delivery of supports and resources. This inquiry lends itself well to the relational component of the PCAP model and provides a new tool for the triangulation of data sources, allowing for comprehensive and shared understandings of best practices in FASD planning, service delivery, and client care.

Manuscript One

Job, J. M., Poth, C-A., Pei, J., Wyper, K., O'Riordan, T., & Taylor, L. (2014). Combining visual methods with focus groups: An innovative approach for capturing the multifaceted and complex work experiences of Fetal Alcohol Spectrum Disorder prevention specialists. *International Journal of Alcohol and Drug Research, 3*(1), 71-80. doi: http://dx.doi.org/10.7895/ijadr.v3i1.129

This paper discusses the untapped potential of an innovative methodological approach for capturing the experiences of prevention specialists working with women at risk of drug and/or alcohol-exposed pregnancies and live births. Allowing frontline workers to express their personal and professional experiences through a creative activity enhanced our understanding of the difficult-to-measure programming outcomes of a provincial FASD strategy. Forty-seven FASD prevention specialists from across Alberta, Canada participated in the study as part of the Annual General Meeting of the Parent and Child Assistance Program (PCAP)—a prevention program for women at risk for drug and/or alcohol-exposed pregnancies and live births.

A multi-method design, integrating focus groups with a quilting activity, was employed which allowed for triangulation across data sources: 7 focus groups and 49 quilting pieces. Thematic analysis revealed four themes: *change as a process, client-advocate connection, ecological understanding*, and *evidence-based practice.* The findings from this study contribute improved understanding about the significance of *relationships, reflection*, and *research* in the work of FASD prevention specialists. It is put forth that a multi-methods approach provided an appropriate and trustworthy means of accessing the prevention specialists' programmatic experience; that experience has the strong potential for informing future FASD policy, strategic planning, and programming.

Manuscript Two

Atkinson, E., Job, J., Pei, J., Poth, C., O'Riordan, T., & Taylor, L. (2013). Capturing the experiences of FASD prevention workers through quilting. *First Peoples Child & Family Review, 8*(1), 122-129.

Visual data collection methods are gaining momentum in the field of qualitative research because of their ability to document the social world and experiences of participants (Banks, 2001; Rose, 2001). This study employed quilting as a data collection method to capture the experiences of 47 FASD prevention workers in the PCAP across Alberta. Specifically, this article focuses on the process of creating the quilt, the impact that this data collection method has had on participants and researchers, as well as a discussion of our next steps and suggestions for future opportunities to use quilting methods in community-based research.

Assessment

One study highlights the need for a fundamental shift in the purpose and direction of assessment. Researchers report that concerns and complaints about assessment have remained for decades, and that little change has occurred to improve current practices (Mastoras, Climie, McCrimmon, & Schwean, 2011). If school psychologists, allied professionals, and educators are to effectively meet the learning and developmental needs of children affected by FASDs, a paradigm shift away from diagnostic and funding goals toward informed interventions must happen. Stakeholders weigh in on their experiences with psychoeducational assessment of affected students, and ideas for improvement in collaboration, recommendations, and monitoring of child outcomes.

Manuscript Three

Pei, J., Job, J. M., Poth, C., & Atkinson, E. (2013). Assessment for intervention of students with fetal alcohol spectrum disorders: Perspectives of classroom teachers, administrators, caregivers, and allied professionals. *Psychology, 4*(3A), 325-334. doi: 10.4236/psych.2013.43A047

The present study begins to address the need for evidence-based approaches for guiding the psychological assessment of children with FASDs. This project represents an important step toward increasing links between research and practice in the communication and use of assessment results for informing intervention decisions. Using a qualitative research approach, the current study contributes to knowledge about concerns with current psychological assessment practices and offers suggestions for optimization based on conversations with teachers, administrators, caregivers and allied professionals.

Thematic analysis of 11 focus groups and 3 interviews (*N* = 60) yielded 3 major findings: *the need to focus on the whole child*, *the necessity of an assessment process that is responsive*, and *building capacity in the school.* This study increases the links between research and practice as we move toward a model of assessment for intervention. Such a model has a strong potential for optimizing assessment practices to better meet the needs of children with FASDs as it promotes a shift that focuses on successful child outcomes regardless of diagnosis.

Intervention

Two publications report the findings of a large-scale investigation designed to explore school-based assessment and intervention efforts for students with FASDs with some information gleaned about support across home and community settings. Key stakeholders involved in the education of affected students shared their perceptions, experiences, and aspirations through interview and focus group discussion. Of particular importance was the documentation of stakeholder challenge in communication and collaboration as positive working relationships were deemed vital to the transfer of information and successful developmental and implementation of FASD programs and services.

Manuscript Four

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

This exploratory study addresses the call for an increased presence of key stakeholders' perspectives in educational research involving students with 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.

Manuscript Five

Poth, C., Pei, J., Job, J. M., & Wyper, K. (2014). Toward intentional, reflective, and assimilative classroom practices with students with FASD. *The Teacher Educator, 49*(4), 247-264. doi: 10.1080/08878730.2014.933642

The value of research-informed classroom practices is well recognized and thus this qualitative study was designed to explore, from multiple perspectives, the experiences and influences of classroom practices for students with FASD. The inductive analysis of 11 focus groups and 3 interviews involving 60 individuals working closely with this student population—31 teachers, 7 administrators, 16 allied professionals, and 6 caregivers—generated three themes: *understanding the whole student, responding within dynamic environments,* and *optimizing student-centered programming*. This study provides an essential step toward better-prepared educators for meeting the learning and developmental needs of students with FASD as well as other complex populations. The implications for developing professional learning opportunities reflective of intentional, reflective, and assimilative classroom practices are discussed.

CHAPTER III

COMPLIED MANUSCRIPTS

PREVENTION

Manuscript One

Combining visual methods with focus groups: An innovative approach for capturing the multifaceted and complex work experiences of Fetal Alcohol Spectrum Disorder prevention specialists

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Introduction

The use of visual methods for documenting and representing the social world has resulted in improved understanding of participant experiences and relationships in research (Banks, 2001; Pink, 2007; Rose, 2001). One such visual method is *quilting*—an innovative technique that allows the researcher to integrate participants' stories into a meaningful collective experience (Koelsch, 2008). With the aim of gaining an understanding of the experiences of frontline workers involved in the prevention of Fetal Alcohol Spectrum Disorder (FASD), this paper discusses the untapped potential of this methodological approach for capturing the difficult-to-measure programming outcomes of a provincial FASD strategy. The approach was especially relevant for the current population of service delivery personnel involved in the *Parent and Child*

Assistance Program (PCAP), a program dedicated to the support and treatment of women engaged in alcohol and/or drug use, because staff had frequently been recruited for research and program reviews where the process was onerous and the results were of limited use for frontline workers. As such, it was beneficial to include an appropriate and trustworthy new methodology to address specific research questions about specialists' planning, collaboration, training, and service delivery, and to gain insight into how participants' work affects them on a personal level. This inquiry into professional and personal experiences through a multi-method design lends itself well to the relational component of the PCAP model and provides a new tool for the triangulation of data sources, allowing for comprehensive and shared understandings of best practices in FASD planning, service delivery, and client care.

Prevention: The *Why* of FASD

FASD is the leading cause of preventable neurodevelopmental disability in North America, with a conservative incidence rate of approximately nine out of every 1,000 live births (Sampson et al., 1997). FASD results from maternal alcohol consumption during pregnancy and has implications for the child, family, and community, as its features include lifelong deficits in a myriad of domains (Chudley et al., 2005; Streissguth, Sampson et al., 1994), including cognition, executive control, adaptive and social functioning, memory, language, motor coordination, and mental health (Burd, Klug, Martsolf, & Kerbeshian, 2003; Connor & Streissguth, 1996; Kelly, Day, & Streissguth, 2000; Pei, Denys, Hughes, & Rasmussen, 2011; Rasmussen, 2005). Given its breadth of deficits and diversity of impact, FASD is increasingly recognized in Alberta as a serious and complex issue warranting targeted attention in all government service domains—including healthcare, education, and justice—to ensure appropriate understanding of the condition and support for those affected.

A lack of comprehensive supports for individuals with FASD leads many to experience secondary disabilities including homelessness, unemployment, criminal involvement, mental health problems, addictions, confinement, school dropout, sexual deviancy, and problems with parenting (Steinhausen & Spohr, 1998; Streissguth, Barr, Kogan, & Bookstein, 1996). The possibility of such adverse outcomes necessitates a clear and delineated system of support, which can only come from an understanding of *why* services are required and *how* the needs of individuals with FASDs and their families can best be addressed (Poth & Pei, 2012).

Recognizing that FASD is preventable must come with the understanding that it is a multifaceted and complicated social and public health concern. For example, the risk of alcohol and/or drug use during pregnancy may be compounded by several factors, including an adverse personal or family history of substance use, poverty, depression, FASD diagnosis, relationship difficulties, and living in a culture tolerant of heavy drinking (Leonardson & Loudenburg, 2003). With such a range of issues intensifying the challenges faced by women at risk, effective prevention efforts need to be directed toward the coordination of supports and services across domains. It is in this way that the answer to *why* (prevention) shapes the pathway for *how* (service delivery), encompassing system collaboration, relationships, and evidence-based practice (Poth & Pei, 2012). But how do we go about collecting this information effectively and comprehensively?

Visual Methods: The Untapped Potential

A long-disputed concern within qualitative research is how best to represent participant experiences accurately (Galman, 2009). The magic of an image is its ability to convey multiple messages, provoke questions, and express thoughts and emotions in ways words never could. The multiplicity of messages in visual data makes it useful for the efficient communication of academic knowledge (Weber, 2008). What is emerging is the idea that information may need to be *shown* as well as *stated,* so as to reveal elusive, ineffable aspects of knowledge and experience that might otherwise remain hidden. Further, visual mediums allow access to perspectives without the interpretation involved in reading; we can *"see someone else's point of view and borrow their experience for a moment"* (Weber, 2008, p. 45). As a result, empathetic understanding in viewers is enhanced when they are shown visual stories that compare with their own experiences. Seeing or feeling the details of a participant's lived experience through images, shapes, and colors commonly associated with certain sentiments or events increases the trustworthiness and validity of visual information (Weber, 2008). Similarly, Eisner writes, *". . . artistically crafted work . . . creates a paradox of revealing what is universal by examining what is particular"* (1995, p. 3).

The inclusion of visual methods in qualitative research permits the acknowledgement that learning is not solely intellectual, but that all senses provide information to which we respond, and researchers are not excluded from this experience (Emmel & Clark, 2011; Weber, 2008). These methods therefore afford greater flexibility than more traditional approaches (e.g., surveys and interviews) to researchers working in a range of contexts and populations. In the present study, visual approaches enabled us to honor the person behind the information, which in this context was especially significant. As researchers, we agree with Eiser (1995) that the time has come to expand our notion of what constitutes trustworthiness within our research designs, as well as our idea of how academic knowledge can be conveyed and understood.

Study Context

Background. Many FASD-related programs and services are in their infancy in both development and scope as basic scientific knowledge and other building blocks for highly effective FASD supports need to be further developed (Gould, Job, St. Arnault, Pei, & Poth, 2012). To address this, the Government of Alberta (2008) established the FASD Cross-Ministry Committee (FASD-CMC), a partnership of government ministries and provincial and community organizations, for the coordinated development of a unique framework for addressing FASD—the FASD 10-Year Strategic Plan. This made-in-Alberta plan focuses on developing and providing community-based solutions, making it easier for those affected by FASD to receive needed support and resources (Health Council of Canada, 2011). The present study is part of a larger research project designed to evaluate the progress of FASD policy, strategic planning, diagnostic services, and programs during the fifth year of the plan. Areas of research and evaluation include awareness and prevention, support for individuals and caregivers, stakeholder engagement, and training and education (Health Council of Canada, 2011).

The Parent and Child Assistance Program (PCAP). The study participants are FASD prevention specialists involved in PCAP across Alberta. The program is designed to prevent drug and/or alcohol-exposed live births among high-risk mothers (Grant, Streissguth & Ernst, 2002) who have substance abuse issues and are disconnected from community services; these women are exceptionally vulnerable and are in dire need of support and resources (Ernst, Grant, Streissguth, & Sampson, 1999). The foci on *reducing risk* and *emphasizing the client-advocate relationship* are features which distinguish the PCAP model from interventions that force women to remain completely abstinent from drugs and/or alcohol (Ernst et al., 1999).

Upon enrollment in PCAP, clients are matched with highly trained and supervised paraprofessional advocates who share a common history with these women. Clients are enrolled in the program for three years; support is provided through their relationships with the advocates, who complete home visits, offer guidance in effective family planning, give support in attending drug and alcohol treatment, and help in connecting clients with appropriate community services (Grant, Ernst, & Streissguth, 1999). Providing children with a safe home environment and consistent healthcare is of the utmost importance (Grant, Ernst, & Streissguth, 1996). To facilitate client success, PCAP specialists are guided by several key objectives, which include establishing a solid client-advocate relationship, developing client-directed goals, and linking to quality community service providers; role modeling and teaching basic skills; and evaluating the client's progress (Grant, Ernst, Streissguth, Phipps, & Gendler, 1996).

The Alberta PCAP approach is modeled after the Seattle Advocacy Model, which has demonstrated remarkable results. Between program exit and follow-up ($m = 2.5$ years), Grant and colleagues (2003) noted the following successes: an increase in abstinence for six months or more (0% at enrollment to 31% at exit), a decrease in subsequent pregnancies and alcohol-exposed live births, an increase in permanent housing, and a decrease in public assistance as a main source of income (87% at enrollment to 51% at exit).

Our research begins to address the need for in-depth understanding of the programmatic experiences of Alberta-based FASD specialists who work with women engaged in high-risk behavior to prevent future births of children prenatally exposed to drugs and/or alcohol. This study forwards an innovative methodological approach, integrating focus groups and a quilting activity, in order to address the following research questions: (1) How do FASD specialists work collaboratively in the planning and delivery of related provincial government programs and services? and (2) How are research and best practices used to inform decision-making and practice?

Methods

A primary goal of the multi-method design, integrating focus groups with a quilting activity, was to capture the programmatic experiences of FASD prevention specialists from across Alberta, Canada, using an innovative methodological approach that was both appropriate and trustworthy. The methodology was appropriate in that it took into consideration the diversity of client and staff factors, and the emphasis on human connection that is so valued in work with individuals with FASDs and women at risk of drug- and/or alcohol-exposed live births. It was trustworthy in that it met the standards associated with qualitative data (Creswell, 2008). The combination of focus groups and visual methods enabled each participant to share his or her story through conversation and creative expression (quilting). The novel inclusion of a quilting exercise came about through a discussion between the director of PCAP and her friend, a psychologist and quilter with 15 years of experience, about better ways to capture the lived experience of FASD frontline workers and families affected by the disorder. When this conversation was shared with researchers, they suggested that incorporating a quilting activity into the present study would allow for improved ecological understanding and provide new information about the value of visual methods in FASD research. Thus, two data sources were integrated (i.e., focus groups were paired with a visual method, specifically a quilting activity) to enhance methodological rigor and address the notion that reality (i.e., experience) cannot be fully represented through one medium (Emmel & Clark, 2011).

Study participants were 47 FASD prevention specialists (45 female, 2 male) from across Alberta who were involved in PCAP service delivery and were attending the Alberta PCAP Council Annual General meeting in March 2012. Included in this group were service providers, network coordinators, program managers, administrative personnel, and leadership team members. This diversity of roles and representation from all 10 Alberta networks gave researchers confidence that this sample was demonstrative of the PCAP population and that the quilting pieces produced reflected a range of experiences, emotions, and clientele. All 47 participated in the quilting activity; however, only 41 agreed to also participate in one of seven hour-long focus groups. The groups were organized by role to facilitate open and honest conversation (see Figure 1). Four discussions were held in the first hour, while the remaining participants completed the quilting exercise. The participants then switched activities to ensure that each one had the opportunity to be involved in both data collection phases. Consent for the quilting activity was implied through completion of a piece; participants provided written consent for the focus group portion of the study.

The quilting activity involved participants using a variety of materials (e.g., fabric, markers, glitter glue) to create quilting pieces that expressed their experiences working in PCAP through illustration and/or words. Although a facilitator was present to guide the process, directions were purposefully vague (i.e., “Using words or illustrations, tell us about your experiences in PCAP”). An example of a completed quilting piece was available for viewing, but this piece was unrelated to the topic and was displayed mainly to demonstrate how to use fabric markers and gel paint, and how to prepare a piece that would work as part of an assembled quilt (e.g., thick gel paint lines or excessive coloring may bleed; a one-inch space around illustrations was necessary to ensure they would not be cut off in the sewing process). On the backs of the squares, participants included their name, role, and explanation of their piece. As documentation, photographs of the quilting activity and quilt construction were taken, and relevant comments from participants (e.g., feedback about quilting) and our master quilter (e.g., her process of analysis) were noted. For the focus group sessions, a team of experienced researchers used a semi-structured protocol to capture participant experiences using such guiding questions such as “Tell us your story about how the PCAP program has changed over the past five years” (see

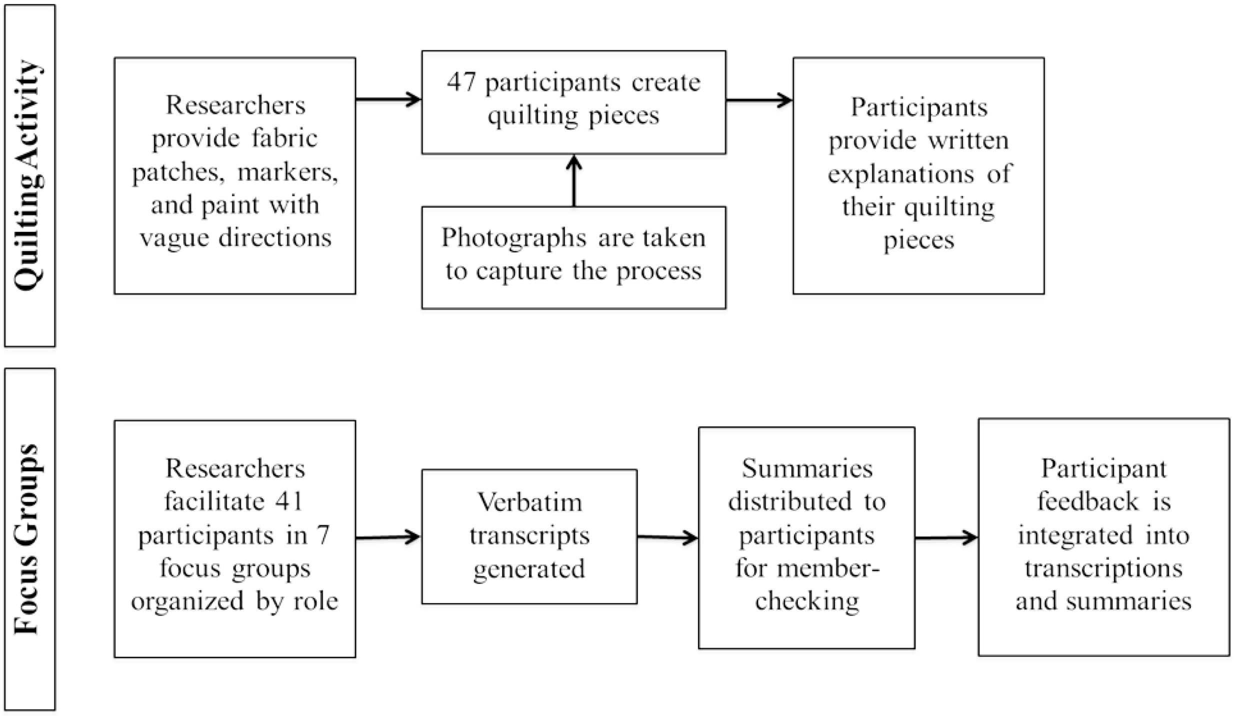

Figure 1. **Summary of data collection of quilting activity and focus groups**

Appendix A). The audio recordings of these sessions were transcribed verbatim, and member checking was undertaken through the distribution of summaries generated during a preliminary analysis and solicitation of participant feedback, which was then integrated to ensure data accuracy and response completeness (see Appendix B). Data analysis involved two sequential phases: within individual data sources followed by integration across data sources (e.g., within and across focus groups and quilting pieces) (see Figure 2). The individual and cross-focus group analysis followed an inductive and iterative process undertaken independently by two researchers, meaning that coding was generated through transcript readings but code definitions and applications were informed by previous and subsequent transcript readings. Similarities and differences between codes and definitions for each transcript were compared, and an inter-rater reliability of 90% was achieved and code lists finalized. Categories were generated from tracking tables using the codes relating to service deliverers' experiences engaging in collaborative

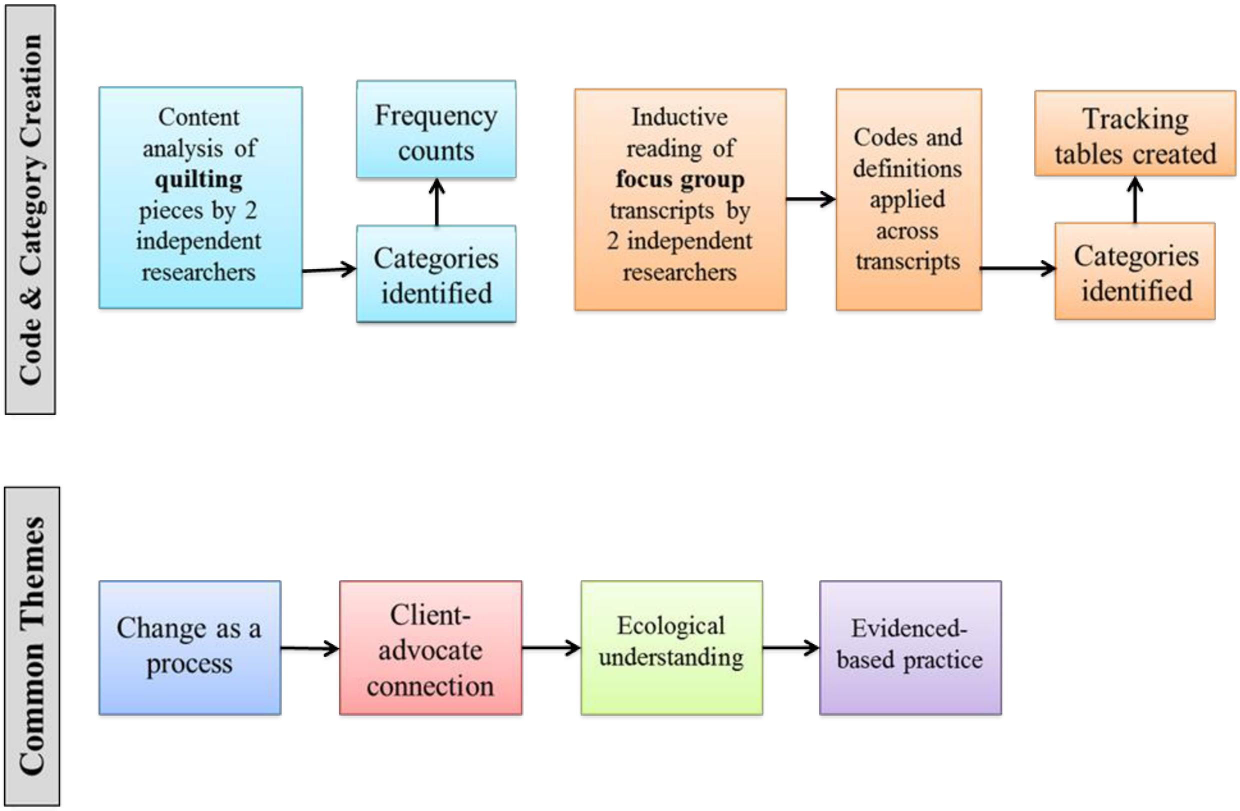

Figure 2. **Summary of thematic analysis framework**

practice and evidence-based decision-making across focus groups. A subsequent review of transcripts and code lists by a third researcher enhanced confirmability (i.e., the degree to which the themes were grounded in the data) and dependability of themes (Lincoln & Guba, 1985). The master quilter and a researcher individually undertook the content analysis of the participants' quilting blocks including frequency counts (e.g., shapes) and inductive generation of categories (Galman, 2009). Specifically, attention was paid to common words, images and colors across the pieces, resulting in a hierarchy of categories beginning with *pain and grief* and ending with *hope and vision* (see Figure 3). Additionally, researchers engaged in continual examination of the quilting pieces and focus group data for similarities and patterns (Ausband, 2006; Savenye & Robinson, 2003). The integration of data sources was guided by a constant-comparison

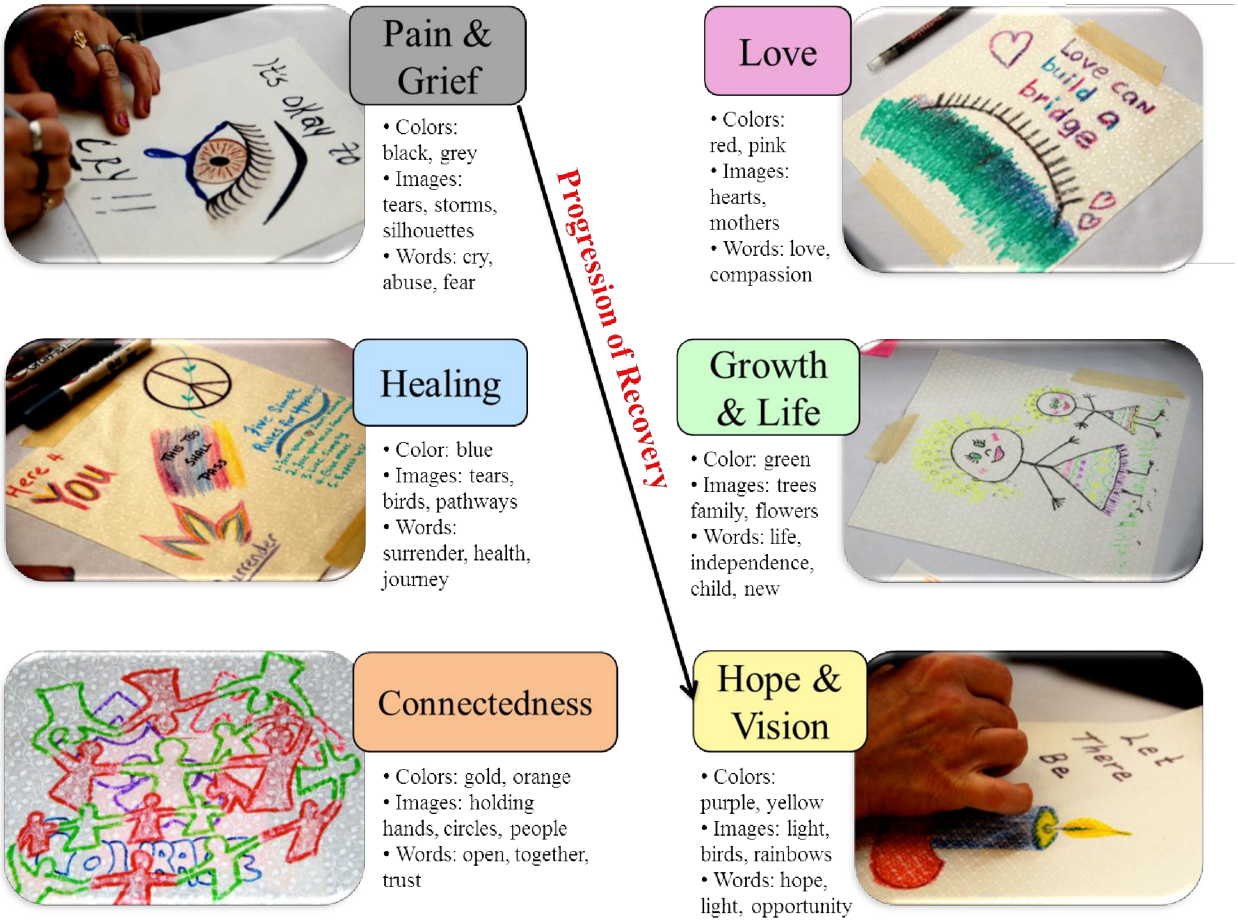

Figure 3. **Categories of the quilting activity**

approach, whereby categories from the quilting activity were compared for both congruence and dissonance with those from the focus groups. Consensus for final themes and subthemes was achieved through discussion amongst the coders, reviewers, and two principal investigators.

Results

Four themes revealing participants' emotion, candor, and passion as well as their commitment to the care and advocacy of women and children affected by FASD were generated: *change as a process, client-advocate connection, ecological understanding,* and *evidence-based practice*.

Change as a Process

Many of the quilting pieces captured the change progression associated with client recovery as a process rather than a single event, while focus group participants discussed changes in program delivery over time. The round shapes, cursive letters, and fluid images (e.g., paths, water) common to many quilting pieces suggest that service delivery personnel have a mindful view of how relationship-building is developmental. The inclusion of images such as eye, tear, hand, heart, tree, sun and rainbow suggest a movement through recovery—acknowledging pain and envisioning a better and possible future. This idea is further triangulated by illustrations, quotes, words, and colors related to different aspects of the recovery process, moving from pain and grief, to healing, to growth and new life. This is not surprising, as the complex and chaotic lives (which may involve history of abuse, legal problems, mental health issues, and poverty) of vulnerable women and children leave these clients at different stages of readiness for change.

The majority of focus group participants reported tremendous growth in their field, fueled by increased government involvement and the emergence of new program sites in various locations across Alberta. These changes have led to a greater number of individuals with FASDs being able to access and receive services, as well as an increase in public awareness campaigns. As one participant explained, “Within the program itself, I think . . . the biggest change is working with that exponential growth. I’ve been with [PCAP] for two years and we’ve gone from four clients to fifty-two...” Despite the challenges of working with this specialized population, an overall optimism was apparent, deriving from participants’ belief in the importance of their work and their clients’ potential for positive change and growth.

Client-Advocate Connection

Across focus group discussions and quilting pieces, the connection between clients and advocates was described as paramount to the success of treatment and prevention services. Among the major strengths of PCAP is its focus on relationship building, in terms of approaches for working with clients, reflective supervision, supporting colleagues, and collaborating with other service providers. In the quilting illustrations, connectedness was suggested through images of holding hands, pathways, circles, and people in orange and gold coloring. Similarly, focus group participants emphasized the flexibility of the PCAP model and its emphasis on non-judgment as crucial when working with special populations, and key to the establishment of the client's trust in the process of recovery and the person lending support. As one participant explained: "… programs and strategies don't heal people, relationships do and that's just so important . . . It's not the programs that are great programs, it's the individuals who are [leading them]." The importance of trust was shown in the quilting pieces through depictions of closeness between people; the inclusion of hearts, interlocking hands and overlapping figures; and the use of words like "together," "trust," and "love." In focus groups, participants reported that their work was directed at increasing client self-efficacy and that a woman's sense of connectedness to others is central to her growth, development, and definition of self. Rather than adopting a *me-you* perspective, PCAP advocates strive to create a mindset of *we,* believing that women with drug and/or alcohol addiction should never feel isolated in their journey of recovery. As one advocate expressed in the focus group sessions:

> Nobody ever gave them a chance. Now, they finally have somebody to support them to actually succeed and move forward in their lives instead of being stuck in . . . their addictions and having babies and losing them. [It can be a] vicious cycle that they get

> stuck in. So just having somebody there to help them [get] unstuck, [that is what's important] . . .

Ecological Understanding

The need for improved understanding of individuals with FASD and the advocates who work with them across services and contexts emerged as a common theme. The quilting pieces revealed stories of pain and grief but also of overcoming and hope. Several focus group participants commented on the therapeutic aspect of the exercise, saying that they "couldn't have guessed how [their] pieces would have turned out," or that the feelings and thoughts expressed had been buried deep inside. This suggests a need for increased reflection on how our work is affecting our clients and ourselves, which demonstrates the usefulness of creative outlets that allow us to tell a story. It also shows how cathartic and exploratory such exercises can be. Although the quilting pieces revealed hopefulness, connectedness, compassion, and strength—demonstrating the participants' passion, dedication, and belief that their work can and does make a difference—the desire for meaning in activity appears to be central to their request for continued professional learning and personal growth. The quilting pieces provided evidence of the humanistic and relationship-based approaches of PCAP, illustrating acceptance and value of the client and the human, and the reality of our need for caring communities. This sentiment was corroborated in focus group sessions; as one participant stated, "There are no throwaway people." This highlights the need for us to do our best to help our clients become the most capable women and mothers they can be. No matter the struggle, each person is valuable and has the capacity for positive change.

Evidence-Based Practice

The majority of focus group participants reported that their prevention programs were strongly research-based, yet there was little reference to the influence of research in the quilting pieces. The same participants also highlighted the fact that PCAP is continuously evaluated, which helps inform prevention activities and affords advocates confidence in the effectiveness of their services. As one participant commented, “[Research-based information on] PCAP not only provides credibility to the work that you’re doing, but it gives you that focus in how you’re going to move forward.” Yet, they were conflicted in their recognition of the need for evidence-based practice. Although they saw research and best practice as useful, they also stressed that accessing current information on such research is incredibly time-consuming. However, several workers stated that they currently receive FASD research by e-mail through their agencies, and were enthusiastic about the potential of a new avenue for research access. As one advocate expressed: “…it’s exciting . . . to look forward to having . . . more research information that can be used . . . [A] database would be awesome [in helping with access]…”

Another key idea emerging from focus group discussions on how to ameliorate research access was to increase links between FASD researchers and frontline workers. For participants who had this contact, the experience had been largely positive: “It was very good . . . working with [Jessica], who . . . does a lot of workshops around FASD. She’s my mentor, and so it really helps to have someone who is that knowledgeable around FASD to be your support and in your corner…” Indeed, increased opportunity to network with researchers was delineated as critical to the improved use of research, as was establishing evaluations for programs to increase evidence-based practices in the field.

Discussion

Just as the metaphor of the quilt emphasizes the personal stories within a collective work, so too can research be used to provide connections between different methods through data integration (Koelsch, 2008). Whether visual or oral, information about participants' experiences is gleaned and made available for comparative analysis to establish key elements of FASD prevention and service delivery, and to identify where strengths and challenges lie in working toward the best possible outcomes. The integration of focus groups with a quilting activity provided an appropriate and trustworthy means of accessing the prevention specialists' professional and personal experiences, which have important practice and methodological implications. While the integrated findings of this study have the strong potential for informing FASD policy, strategic planning, and programming, the account of the study's innovative methodological approach provides a real-life example of its usefulness within this type of research context. In a time when research is increasingly expected to show its relevance to policy and social change, images have the ability to reach a wide audience, breaking through common resistance and engaging viewers in a new way of *seeing* FASD (Weber, 2008). Sharing the quilt with government officials involved in the FASD-CMC may provoke critical questions about the value of FASD services and spark individual and collective action toward superior strategic planning and programming in this area (Deshpande et al., 2005). It is also plausible that emotional engagement created through visual research data may push policymakers to listen to advocates' concerns and suggestions more readily, providing a different framework for the health, justice, social, and educational issues surrounding FASD.

The findings from this study contribute improved understanding of the significance of *relationships, reflection*, and *research* in the work of FASD prevention specialists. It is through our interactions with others and our diverse experiences that we truly learn about ourselves; thus, a research approach that incorporates reflection, subjective awareness, connection, communication, and creativity can provide significant value to a project and the participants involved (Wright, personal communication, 2011). This idea is also wholly consistent with the PCAP model, which invites openness and candidness from clients, advocates, and supervisors alike (Ernst et al., 1999) and encourages learning through reflection on past and present experiences and taking an honest look at oneself.

The novel inclusion of a quilting activity along with focus groups also allowed for reciprocity in teaching and learning between researchers and participants, giving rise to enhanced ecological understanding (Job et al., 2012). As O'Sullivan and Taylor (2004) describe, "[Knowledge is] not individually derived and held but . . . generated in relationships with others" (p. 21). It is important to note the transformational effect that involvement in this multi-method study had on research team members, many of whom had no prior knowledge of or involvement with the FASD world. As one doctoral student relayed, "In our research, we are usually focused on the child, their deficits, and the interventions needed . . . This focus on prevention and the struggles that are involved in working with this population definitely added to my understanding." Added to the participant summaries was a supplement of reflections from researchers, detailing how collecting the data had personally impacted them. This provided further value to participants, who believed their input normally fell on deaf ears, in that they were able to read about the effect of their words and illustrations on the researchers. It also encouraged researchers to reflect on their involvement and the importance of making an authentic connection with participants in community-based research (Job et al., 2012).

With respect to research, participants expressed a fervent desire for FASD-related research and program evaluation to further evidence-based practice, a need that is consistent with the literature (Baugh et al., 2011). Participants also suggested a greater push to work with other agencies to bring FASD to the forefront of public awareness and increase accessibility to community services, as best practice means advocates cannot work in isolation (Brown, 2004). This is noteworthy, and ties in well with the argument for a multi-method approach to data collection. If a primary goal in FASD strategic planning is to enhance community awareness (McCarty, Waterman, Burge, & Edelstein, 1999), it only makes sense to incorporate ways to increase understanding and accessibility of information into research methods. PCAP advocates recommended the creation of an online database to enhance information sharing and communication between FASD researchers, frontline workers, provincial networks, and community agencies. Access to consistent and timely reporting of program outcomes has the potential to increase collaboration between frontline workers across communities and settings (Pei & Poth, 2009). Additionally, the usefulness of the quilt lies in its visual presentation of information, telling individual stories and enabling community partners to see how the parts make up the whole (Weber, 2008), helping them to contextualize the material they read and see the real people behind it.

Limitations

The current study is limited by the methods used for sampling, data collection, and analysis. The first is related to the study’s use of convenience sampling; that is, the sample consisted of those attending the Alberta PCAP Council Annual General meeting who were willing to participate. It might be important for a follow-up study to confirm findings across the entire PCAP population. The second is related to the study’s use of focus groups and a quilting activity; the data from the focus groups is limited to what participants were willing to share in a small-group format, and information from the quilting activity is limited to what participants were willing to express visually. The third is related to the study’s use of thematic content analysis and constant comparison. While these approaches are inherent in grounded theory methodology, thematic interpretation has been used in tandem with a constant comparison approach, which has been described as “taking one piece of data (one interview, one statement, one *theme*) and comparing it with all others that may be similar or different in order to develop conceptualizations of the possible relations between various pieces of data” (Thorne, 2000, p. 2). Given the interpretative experience of quilting, measures were undertaken to mitigate researcher bias (i.e., member checking, multiple coders) to accommodate the two different levels of analysis in the project. Further research is needed to (a) address the limitations highlighted within the findings, as well as to (b) replicate this study for greater generalization and understanding of the PCAP experience.

Conclusions

Visual methods should be considered in research, as they add a personal element to a traditionally impersonal process. What makes them unique is that they represent an effort to understand a participant’s lived experience, recognizing the wisdom that comes from consideration of the whole self—head, heart, and body (Job, O’Riordan, & Taylor, 2012). To this end, it is argued that creative expression through quilting holds promise as an avenue for making sense of and expressing experience, especially among those whose work involves *emotional labor* (Hochschild, 1983) (e.g., nurses, doctors, flight attendants), and for whom emotional expression may be undesirable in the confines of the workplace. In the present study, the use of focus groups with quilting allowed us greater insight into what it means to work as a prevention specialist in the field of FASD and how this work plays into the emotional and relational self. As well, the combination of methods helped to generate a comprehensive and shared understanding related to best practices in relationships, reflection, and research, with the goal of affecting FASD policy, strategic planning, and programming. There is still much work to be done;

however, seeing the participant value of a multi-method approach and potential for increased dissemination and influence gives us hope for positive change, more nuanced knowledge claims, and an improved framework for research in the field.

Acknowledgements

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- The Alberta Community-based Collaboration and Evaluation Research Team (ACCERT) for project conceptualization, data collection, analysis, and reporting;
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- The men and women of PCAP whose dedication to FASD prevention is both noteworthy and inspiring.

We are truly appreciative.

Manuscript Two

Capturing the experiences of FASD prevention workers through quilting

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Introduction

Qualitative methods have long been considered a means of understanding and exploring the meaning that individuals and groups ascribe to aspects of their lives (Creswell, 2008). This meaning is most typically sought through words; collected through interviews or focus groups. However, qualitative approaches also encompass a range of visual data collection methods, such as photography and quilting, which have been gaining momentum because of their usefulness in documenting and representing the social world and improving understanding of participant experiences (Banks, 2001; Rose, 2001). In many ways, visual media allows us to access the perspectives of participants more directly, as we can "see someone else's point of view and borrow their experience for a moment" (Weber, 2008, p. 45). In particular, quilting has been recognized as an innovative visual technique that allows the researcher to integrate participants' stories into a meaningful collective experience (Koelsch, 2008), as was one of the goals in working with our participants, members of the Parent Child Assistance Program (PCAP).

Although quilting is relatively new in its use as a data collection method, previous studies have found that quilting is associated with cognitive, emotional, and social wellbeing, and is experienced as therapeutic by participants (Dickie, 2010; Burt & Atkinson, 2011). Quilting has also been used as a medium to help participants tell their stories related to significant life events (e.g. transitioning out of homelessness; Washington, Moxley, & Garriott, 2009). The following article will outline the process of creating the quilt, explore how this experience has impacted both the participants and the researchers, and discuss how this study might inform future community-based research projects involving front-line workers in other FASD prevention and support programs.

The Program

PCAP is an evidence-based home visitation program for women with a history of alcohol and drug abuse who are at risk of giving birth to a child with a fetal alcohol spectrum disorder (FASD). Originally developed by Therese Grant and colleagues in Seattle, WA, PCAP follows an advocacy and case management model in which PCAP mentors help their clients access needed services, complete addictions treatment, and make informed family-planning decisions (Grant et al., 2005). The goals of the PCAP program include assisting at-risk mothers in seeking addictions treatment, ensuring that children are in a safe environment, and linking families with community resources; all with the ultimate goal of preventing future alcohol-affected births.

PCAP is recognized as a promising program for the prevention of FASD and is currently being implemented in both urban and rural settings across Alberta, (Rasmussen et al., 2012) with seven of these PCAP sites operating on the First Nations’ reserves of Enoch, Blood, Ermineskin, Saddle Lake, Tsuu T'ina, O’Cheise, and Samson. The fundamental components of PCAP are largely consistent with First Nations’ culture in that they emphasize the importance of family and community, they involve strength-based approaches that focus on hope and often involve the use of humor, and they tend to take a holistic approach to client care, with a focus on mind, body, and spirit.

The Purpose

This quilting project was undertaken as part of a larger examination of FASD service delivery in Alberta. Specifically, the purpose of this project was to explore PCAP prevention workers' experiences working on the front lines of FASD prevention efforts in the province. These experiences were collected through a variety of methods (e.g. focus groups), and were further enhanced through the creation of a quilt serving as a visual depiction of participants' collective experiences in the often challenging work that they do. The PCAP program, given its strong evidence base, is subject to frequent research studies and reviews often involving survey methods, the results of which PCAP mentors have reported are of little relevance to their work. Quilting was therefore chosen as a data collection method for this population in part to engage participants and provide them with an outlet for sharing their stories and feeling heard while engaging in a collaborative process, something that was not being accomplished through previous research.

The Process

Forty-seven PCAP prevention workers (45 women and 2 men) from sites across Alberta participated in this quilting project. Included in this group were PCAP service providers, network coordinators, program managers, administrative personnel, and leadership team members, with representation from all 10 FASD Service Networks across the province. We are therefore confident that this sample was representative of the larger population of PCAP prevention workers and that participants brought a variety of experiences with differing client populations to this study.

Participants were given an eight-inch quilting square and a selection of markers, glitter glue, pencil crayons, and pastels. They were asked to use these materials to share their experiences in working in PCAP using illustrations and/or words. Although a sample square was provided to demonstrate the logistics of creating a quilting square, participants were purposefully given limited directions for this task in order to encourage their creativity. On the back of squares, participants included their name, role, and explanation of their piece. Photographs were taken to document this process, and participants' comments throughout the creation of their quilting square were noted. Overall, participants found the process of creating the squares to be a positive and healing experience; as one participant reported "[This] was a great way to start the morning…very therapeutic". Another participant noted that, "hope [was] the major source" of inspiration in creating her piece.

Once completed, the individual squares were collected and given to a master quilter and fellow psychologist, who carefully and thoughtfully pieced these individual works of art together into a quilt. This was a lengthy and intensive process, a labour of love, which involved an interpretation of the content of the quilting squares and the development of an overall theme, layout, and name for the quilt. The quilter documented her experiences creating the quilt and provided commentary on her process and reactions in an interview conducted by a member of the research team.

The Product

The final product is a quilt called *Pick-Up Sticks* (see Figure 1). The quilter chose this name to reflect the challenging nature of a PCAP mentor's work, which involves supporting at-risk mothers in difficult circumstances to prevent FASD. *Pick-Up Sticks*, a child's game, is a metaphor for this process in that PCAP mentors must patiently and lovingly tease out the interventions and services that will be the most successful for each individual client. As in the game, each client is unique and will require a different combination and sequence of sticks (i.e.,

***Figure 1. 'Pick-Up Sticks'* quilt created by PCAP mentors and master quilter, Lin Taylor.**

interventions and strategies) to be successful. As the quilter expressed:

> [Pick-Up Sticks] requires absolute concentration…it requires patience and gentleness and quietness and order to sort out the sticks…That is what needs to be given to people who struggle with FASD…and that's what the people who work with them have to have…unconditional positive regard…That is what we need to give…unconditional positive regard and patience, love, and support.

In addition to the name, each aspect in the design of this quilt has been thoroughly considered. For example, the long scroll shape was chosen to reflect wisdom and higher learning, the green border represents health and growth, while the empty square represents the untold story of those living with FASD.

The quilt is truly inspiring. As you can see, even given the difficult nature of the work these PCAP mentors engage in on a daily basis, the overall feeling of the finished quilt is one of hope and positive visions for the future. The passion and dedication of these individuals shines through their works of art, both in the colours and shapes that they chose to represent their experiences, and in the words they conveyed. For example, squares included images of rainbows, flowers, and growth as well as inspirational phrases such as "love can build a bridge", "when one door closes another one opens", and "together we can." Positive emotional words such as courage, love, hope, beauty, togetherness, happiness, dignity, trust, opportunity, and possibility also abound. As the quilter expressed:

> I was a bit…surprised by how optimistic the quilt was. I expected there to be a lot more of…the cold, hard reality of it and I think that bespeaks the qualities that are necessary in the people who do this work…

The Impact

With the quilt recently completed and being disseminated and shared with PCAP prevention workers and other FASD service providers, we are just beginning to see how the creation of this work of art has impacted those involved; both the PCAP members as our participants and the members of our own research team.

Participant Impact. Upon seeing a photo of the finished quilt, one participant reported being amazed at how all the “little pieces” came together to make something so complex and beautiful, and she felt that it really reflected the nature of the work she does in PCAP, where all the pieces need to come together “just so.” As we continue to disseminate the quilt and related photos to PCAP sites, it is hoped that participants will be able to see the quilt as a representation of their collective experiences as front line workers, and as a tangible product of their hard work and dedication. This stands in contrast to the nature of the work that PCAP mentors are involved in on a daily basis, in which success and tangible outcomes can often be difficult to see and progress difficult to measure. As one participant explained, “It’s hard to measure all the births that we’ve prevented…How do you measure babies that weren’t born?”

Researcher Impact. During this process, several of our PCAP participants expressed interest in learning about how the telling of their experiences affected our team of researchers. The team, composed primarily of masters and doctoral-level students, took time to reflect on our experiences of being involved in such an impactful project. Overall, this process was eye-opening and inspiring, opening our minds to new ways of understanding the work that is done with at-risk populations, and helping us to develop an appreciation for the passion and dedication of PCAP mentors. As one student explained about the entire process:

> I know people are quick to judge mothers and look down upon them for putting

> themselves and their children at risk by drinking, but hearing the stories these front-line workers [told] was a real eye-opener. In our research we are usually focused on the child, their deficits, and [the] interventions they need. This focus on prevention and the struggles that are involved in working with this population…added to my understanding.

Another researcher commented on the quilt in particular:

> [I was] surprised by the flood of emotions that I was experiencing [upon seeing the quilt]… I felt overwhelmed by the powerful messages of hope and struggle depicted in the squares. I was also moved by [the] level of care, commitment and enthusiasm… expressed in… the quilt. I felt like I was taking part in something very special, which I have never really felt in my past research experiences.

We are thankful to have taken part in such a reciprocal process, in which we have had the opportunity to give something back to our participants while also taking and learning a great deal from their experiences.

The Future

The use of quilting methods to capture the experiences of PCAP prevention workers across Alberta has been, by our account, an overwhelming success. The quilt itself has added richness to the data collected by other means (e.g. focus groups), and has produced an understanding of the PCAP program and the passion of its mentors that cannot easily be expressed in words. A formal qualitative analysis of the content of the quilt is currently underway, in which common themes will be explored. Given previous research using quilting methods, we anticipate that this analysis will lead to further understanding of participants' experiences and relationships (Banks, 2001; Rose, 2001).

Furthermore, the production of this quilt has allowed us as researchers to give something back to our participants as a means of thanking them for their participation and validating their experiences as PCAP mentors working on the front lines of FASD prevention in Alberta. We believe this to be important in this line of work, in which there is much uncertainty about future outcomes and where success is often difficult to measure. Future research projects might consider the use of quilting and other visual data collection methods when working with other community-based groups and organizations, as they add an element of a personal connection to a traditionally impersonal research process. Particularly with FASD service providers, this innovative technique is a very collaborative and relationship-focused approach, which appears to align well with the culture and the philosophy of many FASD prevention and support programs.

Finally, this study provides an important starting point for considerations related to data collection methods that have the strong potential to engage participants to a greater extent than more traditional research methods (i.e., surveys). The high engagement of participants observed during the quilting activity indicates that an emphasis on visual storytelling supported the sharing of experiences that may not have otherwise been accessible. Implications for researchers may be far-reaching across all study populations but especially relevant for those collaborating with First Nations, Métis and Inuit peoples.

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ASSESSMENT

Manuscript Three

Assessment for intervention of children with fetal alcohol spectrum disorders: Perspectives of classroom teachers, administrators, caregivers, and allied professionals

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Introduction

Fetal alcohol spectrum disorders (FASDs) are a serious health and social concern (Chudley et al., 2005). FASDs are the result of maternal alcohol consumption during pregnancy and have significant implications for the affected person, mother, family and community due to lifelong deficits in several domains of brain function (Chudley et al., 2005). Although literature regarding the behavioral profile of individuals with FASDs is relatively limited (Burd, Klug, Martsolf, & Kerbeshian, 2003), reported neuropsychological and social deficits include cognitive delay, poor executive functioning, limited social awareness, weak adaptive skills, and mental health issues (Burd et al., 2003; Harris, MacKay, & Osborn, 1995; Kelly, Day, & Streissguth, 2000; Pei, Denys, Hughes, & Rasmussen, 2011; Rasmussen, 2005; Steinhausen, Willms, Metzke, & Spohr, 2003). These substantial impairments create daily challenges for individuals living with FASDs. These difficulties can be lessened with appropriate interventions and supports that are especially effective when implemented in a way that involves collaboration among those involved in the child's life across home and school.

The school experience is often significantly impacted for children with FASDs given the frequent presence of specific cognitive and academic difficulties (Howell et al., 2006) as well as behavioral problems. Given the disorder's diverse presentation, there is a strong potential for school personnel to misunderstand the affected child; thus, it is unsurprising that many children do not receive the empathy or accommodations they require and may become frustrated and contemplate leaving school (Duquette, Stodel, Fullarton, & Hagglund, 2006a). Nonetheless, promising research has shown that given the right environment and support, adolescents with FASDs can graduate from high school (Duquette, Stodel, Fullarton, & Hagglund, 2006b) and go on to lead fulfilling and quality lives (Ackerman, 1998; Green, 2007; Ryan & Ferguson, 2006a, 2006b). Therefore, the critical role of appropriate interventions and supports for these children cannot be underestimated.

Assessment versus Intervention

Psychological assessment is often the first step in the development and implementation of appropriate interventions for children with a variety of psychological and educational needs, including those with FASDs (Kalberg & Buckley, 2007). The array of symptoms and deficits associated with FASDs lends itself to the need for comprehensive assessments that identify the affected child’s strengths as well as highlight weaknesses requiring additional support. This information aids teachers and allied professionals to implement suitable programming and provide meaningful accommodations. Although often a helpful and key part of the intervention process, current assessment practices are not without their limitations. In fact, a general dissatisfaction with current psychological assessment and report writing practices has been noted for more than four decades, although little has been done to improve practices and remedy these concerns (Mastoras, Climie, McCrimmon, & Schwean, 2011). Teachers, parents, and other service providers involved in working with children with a variety of special needs and educational requirements continue to express concerns about test administration, report writing, and communication of the results.

Foremost, psychological assessments have been criticized as being disconnected from the interventions they are intended to inform. Examining the usefulness of assessment reports, Knoetze and Vermoter (2007) conducted focus group interviews with 10 remedial teachers in South Africa. These discussions revealed 3 important findings related to the lack of collaborative practice in current assessment practices. First, teachers reported a gap between the psychologist's assessment expertise and his/ her practical knowledge of the classroom environment including teaching strategies and interventions. Second, it was shown that although teachers respect the skills psychologists bring to the assessment process, they believe that they too possess expert knowledge on classroom interventions and should be consulted with when making decisions about programming. Lastly, teachers noted that their input is rarely sought when recommendations are written, resulting in suggestions that have already been attempted by the teacher or that are unrealistic for the classroom. The disconnect between the potential usefulness of assessment and the reality of current assessment practices serve as an impetus for the present study.

Understanding Reports

An essential precursor for educational strategies is that teachers and parents have access to useful psychological reports (Borghese & Cole, 1994). In particular, a report is useful when it is easily understandable (e.g. Cheramie, Goodman, Santos, & Webb, 2007), when information is sufficiently specific to drive interventions (Ryan & Ferguson, 2006a), and when strength-based language is used in addition to highlighting weaknesses. Researchers have reported that the language used in reports (e.g., technical jargon) and the time it takes to decipher recommendations often frustrates teachers and parents (Cheramie et al., 2007; Knoetze & Vermoter, 2007). Workload issues restrict the time teachers have available to read and understand a psychological report. For parents, limitations in education and reading ability pose a challenge for genuine understanding (Harvey, 1997), which can lead to feelings of detachment from the assessment process and impede recommendation follow-through and advocacy (Groth-Marnat, 2009). Despite numerous suggestions for the improvement of psychological reports, specialized reports full of complex language continue to be produced (Harvey, 2006; Mastoras et al., 2011).

Even when report language is not a concern, teachers often feel that the way in which reports are written is too general (Ryan & Ferguson, 2006a), and does not focus enough attention on the identified issue(s). Often teachers feel as though they need to perform their own evaluations after receiving the report to pinpoint specific areas needing support (Knoetze & Vermoter, 2007). Ultimately, the purpose of psychological assessment is to aid in the planning and implementation of individualized interventions focused on improving functioning and achievement (Fletcher et al., 2002); however, if the reports generated address concerns in too broad a manner then their relevance and value are compromised.

Another concern is the continued dissatisfaction with deficit-focused language used consistently in reports (Groth-Marnat, 2009). Assessments often focus on what the child *cannot do*— or what they struggle to do—rather than suggesting areas in which they demonstrate strengths (Mastoras et al., 2011). And yet, research has found that including personal and educational strengths in a psychological report can have a significant therapeutic effect, and that focusing ability rather than solely disability can lead to more efficacious treatment recommendations and long-term growth (Seligman, Linley, & Joseph, 2004). Providing teachers with information about the strengths a child possesses and how these can be used to compensate for learning and behavioral difficulties may help them to tailor and implement interventions that have the capacity to facilitate change. This may serve to lessen the educational frustrations of the affected child as well as relieve some pressures from teachers to modify programming without appropriate understanding of what will work best.

Assessment for Intervention

Taken together, the limitations associated with current assessment practices often lead to confusion and frustration for teachers and allied professionals working with children with FASDs who present with varied psychological, behavioral, and educational needs. Overall, these concerns are not unique to the assessment of children with FASDs but exist for evaluations of children across contexts, ability levels, and cultures (e.g., Knoetze & Vermoter, 2007), demonstrating global challenges with psychological assessment and its usefulness for intervention determination. While the implications of less-than-optimal assessment practices are far-reaching and affect a number of people, they are especially troubling for children who present with involved psychological profiles such as those with FASDs. Given this complexity, the problems created by inefficient and inadequate diagnostic-driven assessment practices are magnified. The time for a move to assessment for intervention has come.

Purpose and Objectives

The present study is part of a larger program of research focused on improving educational practices for children with FASDs (see Job et al., 2013; Pei, Job, Poth, O'Brien-Langer, & Tang, 2012; Poth, Pei, Job, & Wyper, 2014). This study addresses the call for increasing the voice of teachers, administrators, caregivers, and allied professionals (i.e. social workers, counselors, and educational assistants) in research related to school-based interventions and supports. In particular, our findings report on the assessment experiences of key stakeholders involved in the implementation of interventions and support services for children with FASDs

(Job et al., 2011).

With a goal to inform school psychology practice, this study was guided by the following 3 objectives: a) examine the positive and negative assessment experiences and attitudes of teachers, administrators, caregivers, and allied professionals working with children with FASDs; b) determine whether the experiences of these stakeholders are consistent with the general themes of dissatisfaction identified in the assessment literature; and c) propose solutions to current psychological assessment approaches considering the suggestions of key stakeholders, and linking them to emerging research and evidence-based practice in the field.

Methods

A qualitative, phenomenological approach was appropriate given the study's purpose to generate a comprehensive understanding of experiences to inform practical next steps (Creswell, 2013). Semi-structured focus groups were selected as the means for data collection as this allowed researchers to capture individual stakeholder perspectives as well provide a forum for participants to meet others who had experienced similar struggles in the pursuit of diagnostic testing and specialized supports. This interaction also provided those who had faced considerable obstacles with hope when listening to others' stories of successful assessment and intervention. Data collection for this study follows the call for an increased presence of stakeholders' perspectives in educational research involving children with FASDs (Duquette et al., 2006a), facilitating a deeper understanding of the issues in assessment and roles involved parties play in navigating the process (e.g., facilitator of the assessment, recipient of report results, and communicator of the information) (Krueger & Casey, 2000). For stakeholders unable to attend focus group times, interviews were conducted following the same protocol. Trustworthiness and confidence in the data was enhanced by the use of verbatim transcripts, member checking of focus group and interview summaries, 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 having a degree of expertise in special education, a mean of 13.2 years of experience (range 1-32 years), and representing all levels of instruction (7 identified as Kindergarten to grade 5 and 24 identified as grade 6 to 12). Administrators had a mean of 22 years of experience (range 15-30 years) within various roles (2 principals, 4 assistant principals, and 1 head of student services). Allied professionals reported a mean of 10.89 years of experience (range 1-25 years), with the majority (*n* = 12) identifying their roles as educational assistants and the remaining as other (i.e., in-home consultant, reading specialist, guidance counselor, 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 of experience ranged from 6 to 43 with a mean of 17.83 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 2012, using snowball sampling through established clinical networks via email and telephone. 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 population. Criteria for participant selection included: a) experience with a child with an FASD; b) involvement in that child's psychological or neuropsychological assessment (e.g., completing forms, providing an interview, being provided with assessment results, and/or implementing interventions based on report recommendations); c) working with that child 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 by role (i.e., teachers, caregivers) were held, each lasting approximately one hour and following a semi-structured protocol. Regardless of whether stakeholders participated in focus group or interview sessions, the same protocol and probes were employed, with minor adaptations to reflect role-specific experiences. 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 com-munity supports and resources. The number of focus group participants ranged from 2 to 9 with a mean of 6. Two research assistants (interviewer and note-taker) with advanced training in qualitative research facilitated the sessions. The presence of a note-taker allowed the interviewer to remain focused on the interview process. 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) (see Appendix C). Participant feedback and additional comments were incorporated as notes in the transcriptions to ensure accuracy of the data and completeness of participant response.

Data Analysis

Inductive analysis was undertaken in 3 phases: within individual focus groups and interviews, across focus groups and interviews involving the same roles, and finally a cross-analysis of focus groups, interviews, and roles. The integration of data sources was guided by a constant comparison approach (Glaser & Strauss, 1967) wherein codes and categories across focus groups were compared for both congruence and dissonance by two independent researchers. Researchers began by generating codes for one transcript, and then adding on or modifying codes across transcripts within the same roles. Codes were discussed until consensus was reached with the aim of achieving inter-rater reliability of 90%. Code definitions were informed after reading all transcripts. At the end of this process, codes were pared down and assigned to broader categories. Summaries were written for each role and helpful during the cross-analysis, allowing researchers to compare similarities within each role and highlight differences across roles. This allowed for further streamlining of the code and category lists and allowed for the identification of themes and subthemes (see Figure 1) with definitions. Complete coding lists demonstrating the progression from codes to themes were created for each role and then integrated as much as possible into a master list across roles. Important data specific to one role were starred and discussed separately within the findings.

Findings and Discussion

Thematic analysis yielded 3 major findings, which focused on: *the whole child*, *the assessment process*, and *building school capacity*. Interestingly, findings revealed that concerns with and goals for improved assessment processes were not limited to the FASD population but rather all children. The high needs of children with FASDs simply serve to draw attention to the importance of such changes. The following section is organized by theme illuminating key concepts and experiences.

The Whole Child

Increasing the scope of the assessment process, to reflect *the whole child*, emerged as a necessary initiative in the move toward improving diagnosis and intervention. To do this, participants felt that the information gathered must be sufficiently comprehensive to reflect the complex needs of this population. The goal of psychological assessment for diagnosis was

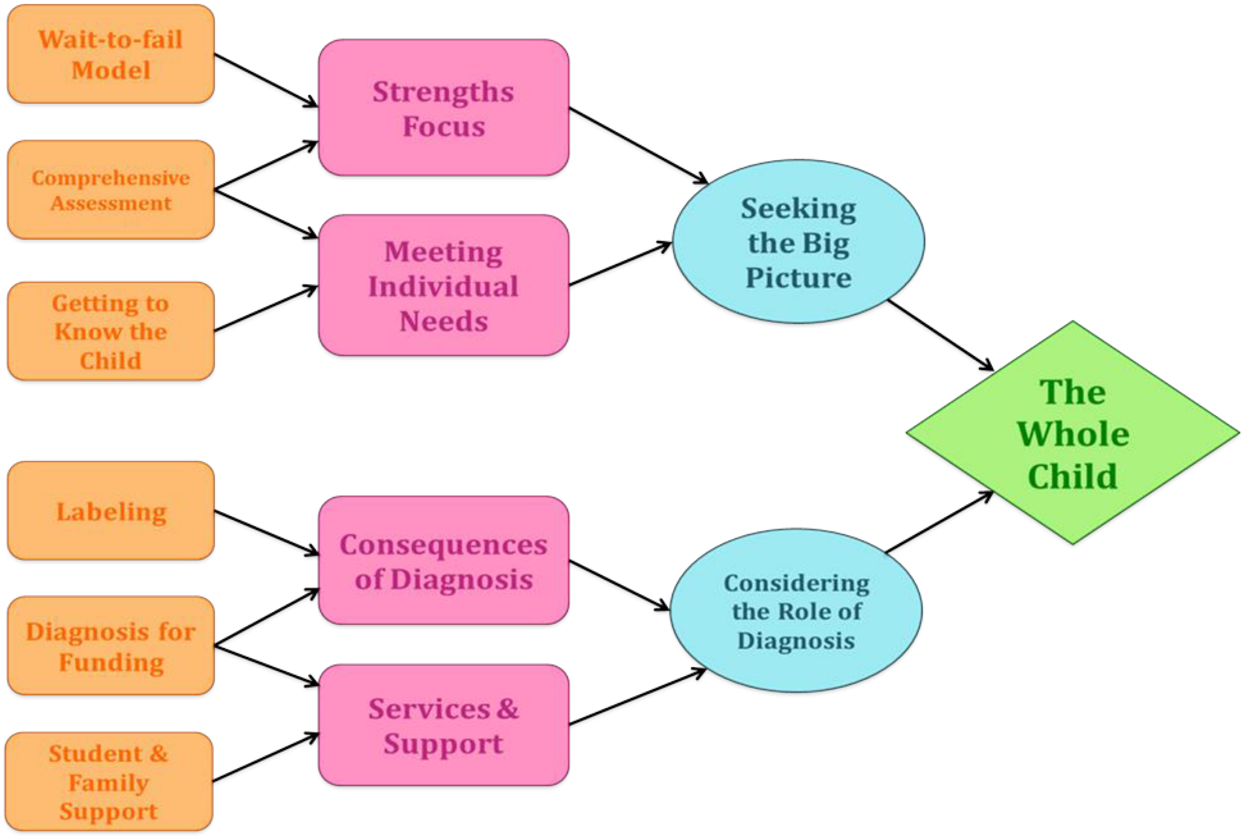

Figure 1. **An example of code and theme development across roles.**

questioned, with the rationale that there is a role for diagnosis within the assessment process to help initiate funding, but that the process can consist of more than the diagnosis alone. In short, two key ideas were detailed: *seeking the big picture* through a more collaborative and thorough assessment process and *considering the role of diagnosis* as a vehicle for resources and support.

Seeking the big picture. The process of gathering information from multiple sources was consistently noted as being foundational to the validity of the assessment process across caregiver, administrator, and allied professional roles. The need for more comprehensive assessments involving multiple individuals and data sources was emphasized in contrast to making a determination for diagnosis and intervention based on limited information. Wynn, an administrator, discussed the process of assessment at her school: “Our psychologist meets with us, gathers the information, [and] observes the kids on two or three days…" The advantages of such a process include a better understanding of the child's strengths and weakness across settings, which enhances the likelihood that the assessment will inform meaningful and feasible interventions, rather than "… just getting a one-hour snapshot."

A disconnect within the process of integrating the assessment data to inform intervention decisions and practices was viewed as being a source of concern as was the quality of written psychological reports. Currently, assessment seems to be focused on the *product* (i.e. producing a psychological report) rather than the *process* of collaborating and involving all individuals who care for the child in order to understand his or her needs. For high-needs populations such as children with FASDs, consistency in assessment process and practice has been revealed in the literature as being key to implementing well-suited interventions. Ensuring all individuals involved in caring for children with FASDs have the same information and understanding, and considering their suggestions and feedback in the assessment and intervention processes is crucial (Blackburn, Carpenter, & Egerton, 2010).

Similar to the call for the inclusion of multiple sources in assessment, participants across all four roles indicated a desire for the incorporation of information useful to strengths-based programming. Caregivers and allied professionals discussed the hindrance of a deficit-model, which emphasizes areas of weakness and perpetuates stigma and stereotypes. The use of a deficit-model proved common in the assessment experiences of participants across roles with only one caregiver experiencing a supportive and strengths-based evaluation: "…[the assessment proved] very supportive…the girl from the psych report [explained] his areas of strength and weakness and learning style…so that they could make accommodations for him" (Jessica).

All participants agreed on the usefulness of information about cognitive and academic strengths in developing appropriate interventions, noting that having the complete learning profile of a child with an FASD leads to greater success in programming and achievement. Concentrating on deficits may enable school psychologists to diagnose disabilities but such practice does not inform intervention and treatment of difficulties (Jimerson, Sharkey, Nyborg, & Furlong, 2004). Conversely, researchers posit that identifying areas of strength (e.g., confidence) may help to address underlying challenges rather than simply managing observable behaviors (Terjesen, Jacofsky, Froh, & DiGiuseppe, 2004). The use of a strength-based approach also allows school psychologists and educators to better understand affected children and their resources, facilitating more complete intervention planning (Rhee, Furlong, Turner, & Harari, 2001).

Considering the role of diagnosis. When considering the consequences of diagnosis for a child with an FASD, caregivers discussed diagnosis as a vehicle for accessing resources. Caregivers tended to view diagnosis as a strength allowing them access to services and accommodations that were previously unavailable rather than a label that would negatively affect their child:

> I felt it's more important that the child gets help than worry about a label…I gave the school copies of all the reports that we had…in fact one of the teachers said to me, 'I'm so grateful to you for communicating this with us. You'd be surprised how many parents don't want us to know the children have some problem.' (Jessica, Caregiver)

Darlene, a caregiver, added that diagnosis provides support in advocating for specialized programming and resources:

> …some of the positive things about having a diagnosis is you've got something to work with and you've got back up. [If] you've got that piece of paper in your hand,

> then you don’t have to back down from anyone.

For school personnel, diagnosis was viewed as more of a guide, affording children and families greater direction and support. As Wynne, an administrator, explained:

> …quite often if the child has FAS, there’s a good chance the [biological] family is. So, they don’t have the structure. They don’t have the ability to come in and share their experiences since schools have not been good…quite often they avoid the school. They’re not coming in there advocating…so, it’s helping them also.

Caregivers may fear assessment and diagnosis for their child believing that it can lead to differential treatment by teachers, peers, and even other family members. However, receipt of a diagnosis can have value, providing a way to identify the affected child’s difficulties and abilities and plan for problems that may arise in future educational endeavors (Temple University Institute on Disabilities [TUID], 2003). A diagnosis can also be beneficial in linking children and families with funding and specialized programs and affording them access to services crucial to success and healthy child development (TUID).

One of the main concerns with either a lack of psychological assessment or less-than-optimal assessment practices is that affected children may be misunderstood, resulting in inadequate or inappropriate educational support. Tom, an administrator, explained this challenge: “…quite often we don’t know because they haven’t been formally diagnosed and they’ve been going through school for many years you know being seen as behavior students…” However, receiving a diagnosis may not be enough for improved understanding of FASD, especially considering the diverse presentation of the disorder in affected children. As Chloe, a caregiver, so eloquently expressed: “… regardless of whether it’s the same label, they are different children…and that’s what…people have to look at. Just because everybody has the same label doesn’t mean everybody’s the same person.” Therefore, the utility of assessment and diagnosis appears hedged in how well teachers, administrators and allied professionals are prepared to work with children with FASDs and how informed they are about the condition.

Despite efforts to differentiate between diagnostic labels and better inform teachers of the disorder (Chudley et al., 2005), such attempts do not necessarily translate into improved teacher knowledge of what challenges he/she may see in the classroom (Clark, 2012). This is why professional development and resources specific to FASD are essential for school personnel and allied professionals working with affected children. In instances where the needs of the child with an FASD are well understood, stakeholders can work collaboratively to provide necessary services, as in the case of Laura, a caregiver:

> …we got [the assessment] nice and early…this is what allowed us to have all this wonderful help...our grandson was given two years in kindergarten and he had occupational therapists and physiotherapists. He had all sorts of things coming into the room because he was eligible for it…early on someone [was] coming to the house to work with him at home…everything was really good but it was all based on that diagnosis.

Researchers have established the importance of accurate diagnosis in determining appropriate interventions and limiting the effects of secondary conditions (Malisza et al., 2005). However, diagnosis necessitates a response that includes the development of a network of support and program planning tailored to the affected child’s specific needs (Public Health Agency of Canada, 2011). Whereas caregivers can help with advocacy and modeling, school psychologists and educators can have an influence through creating and following individualized program plans, establishing smooth transitions, and collaborating with caregivers and community members (Duquette et al., 2006a). Findings from the present study would suggest that while we are striving toward a more collaborative, supportive model of diagnosis and intervention, there is still work to be done.

The Assessment Process

The assessment process itself also emerged as an area of conversation with participants. Many of these discussions seemed linked to the underlying philosophy that accompanies psychological assessment. Assessments may often be seen as a way to react to concerns by identifying the problems that are present. However, what this perspective fails to do is provide any proactive response options with consideration for both deficits *and* strengths with a goal toward identifying what success might look like rather than solely why there is failure (Klin, Saulnier, Tsatsanis, & Volkmar, 2005). Consequently, two key ideas emerged: *responsiveness* of the assessment to prevent the occurrence of greater problems and *finding success* by ensuring professionals are equipped to help affected students achieve success.

Responsiveness. Participants spoke about the logistical components of the assessment process as they contribute to practices that are deficit-focused and reactive due to the boundaries of process (e.g., delay in achievement must be demonstrated before an assessment can be requested). Consequently, they emphasized the need for the process to be responsive to children, educators, and families in order to effectively address learning and behavioral needs and concerns with an eye toward success rather than simply reducing problems. Paramount to this idea is offering assessment services that are timely and accessible. For some participants, the assessment process was smooth and allowed for timely receipt of diagnosis and recommendations, as evidenced by one caregiver, Jessica's account:

> …I requested [a psycho-educational assessment] for him and they were more than

> willing [to do it] right away, no questions asked…I didn't have to fight for it. I didn't have to justify why I wanted it. They were just willing to do it…[and] they had the psych[ological] report done right away.

For others, the wait for an assessment across school and community settings was long yet worthwhile. As Laura, a caregiver noted, "…it takes a number of months to get in [for an assessment]…but it was a very smooth process once we started it. And then there's a whole team of professionals that work with these kids." This experience was echoed by school personnel who reported lengthy waits for an assessment due to psychologists' full caseloads: "…even the assessments that do get done at school…they are well done but they're a very lengthy process" (Nadia, Allied Professional).

Overall, stakeholders underscored the benefits of early assessment by qualified professionals. One teacher specified that a "good, accurate assessment would be really [helpful] to get all the testing done quickly and…by the right people" (Jenna). Working toward an assessment model that allows for early and timely diagnosis and intervention information enables the child with an FASD access to funding for programmatic changes and resources, focusing on growth rather than struggle (Healthy Child Manitoba, 2010).

Equally as detrimental as the wait time identified by teacher and administrators was the wait-to-fail model wherein assessments cannot be accessed until a consistent lack of achievement is shown. Wynne, an administrator, described her view of this system and ideas for improvement:

> …it's kind of frustrating 'cause they now have experienced 3 years of failure because they have to be 2 years behind before they actually get identified. If we can identify them earlier then the school can be set up so that they're helping…streamline

> them into a special education program if they need or at least [let] the teachers adapt…

Evidence of the benefits of early diagnosis (e.g., improved care of primary deficits and decreased impact of secondary disabilities) is well documented (Koren, Nulman, Chudley, & Loocke, 2003; Streissguth & Kanter, 1997) as a useful way to reduce later adverse outcomes. However, some children with PAE meet developmental milestones at age-appropriate times and thus, an assessment at one time point may not provide a comprehensive picture of functioning. For instance, it is only when neurobehavioral deficits arise, including impairment in executive functioning, that information about independent functioning can be gleaned (Koren et al., 2003; Rasmussen, 2005). Therefore, it may be prudent to think of assessment as not simply a diagnostic task but rather a way of gathering ongoing information about a child at key points in their education (e.g. transitional times) to facilitate interventions that adapt to the affected child's changing needs and abilities. It is apparent that too much of a delay for treatment (i.e., the wait-to-fail model or time lags) can lead to a population of students who fall farther and farther behind their classmates (Fletcher et al., 1998).

Finding success. Finding success through psychological assessment means gaining understanding about where a child is at and what would help to address his/her individual needs in order to work toward success. For school personnel, this requires adaptation, flexibility, and knowing your students. As one allied professional, Bob explained:

> …it really depends on the kid. If the kid's capable then…we push to achieve…but I think that I really try to be what the kid needs…it's trying to see what's going on, what are the motivations behind what he's up to, and… then trying to provide him what he needs…

However, part of achieving this degree of flexibility is dependent on the team that participates in the assessment process. It is imperative that the psychologist in charge of the assessment recognizes that it will require a team to develop comprehensive intervention strategies and that the process warrants contribution at all stages. As one teacher noted, intervention planning is best done in collaboration:

> …the support makes you stronger as a teacher too, right?...I learn so much from a [speech language pathologist] and an [occupational therapist] and you learn so many tricks [about] how they modify [things]…they come in and they add something new and it just gets better and better and you get stronger that way and more confident in [your teaching]. (Carla)

Participants stated that it is not enough just to have professionals and families communicate with one another regarding needs and strategies, but that children with FASDs require active collaboration to identify needs and strengths and establish effective strategies. This is commensurate with previous research that emphasizes caregiver involvement in school-based interventions (e.g., Clark, 2012; Kalberg & Buckley, 2007). Such an approach will help with skill building, the improvement of cognitive and learning strategies, and the reinforcement of positive behaviors as well as involve families in the process of advocating for needed and warranted services for their children and themselves. Assessments geared toward intervention can provide the catalyst and guidance for this degree of collaboration.

All participant groups called for increased support for teachers and caregivers from administration and other professionals (e.g., social workers, counselors, and mental health professionals) so as to enhance the understanding of children with FASDs and increase the utility of assessment. A teamwork approach was described as a necessity whereby the workload is distributed among different stakeholders to ensure that affected children receive needed assessments in a timely manner and that shared understandings are reached. To assist in the provision of interventions for children with FASDs, it is essential that professionals working with this population receive adequate training and information about FASD-related deficits and secondary disabilities including the condition's diverse presentation and best practices for assessment and intervention (Gahagan et al., 2006; Green, 2007; Paley & O'Connor, 2009; Paley et al., 2009).

Building School Capacity

If a psychological assessment is to draw nearer to improved understanding geared toward creating success for the whole child—within assessment activities as well as through the assessment process—then it is crucial that the assessment not stand-alone. Instead, strong links between stakeholders and effective communication strategies are important. To this end, stakeholders emphasized the importance of a third theme focused on *building school capacity* in which two related challenges of the assessment process are emphasized: 1) clarity of written communication that fosters understanding and facilitates the development of interventions; and 2) transferring assessment information to key stakeholders in a way that enables implementation of useful recommendations for increased learning and development.

Information sharing. The discussion about assessment reports centered around two unique topics: ease of sharing assessment results with school personnel and difficulty in understanding report content. With respect to the former, it appears schools are quite willing to receive assessment results and better understand the affected child's strengths and weaknesses:

> Most of the time I haven't had difficulty sharing the assessment and diagnosis. I'm also a very strong advocate for my son…if somebody is a little bit…apprehensive or leery about it, it doesn't matter to me because I can over- come that and just talk

> about…the positive things and the things that he can do and the supports we need to put in place… (Jessica, Caregiver)

However, for those unfamiliar with assessment, the process can be quite intimidating, especially for caregivers who have heard often the weaknesses of their child. As such, the debriefing session is not always a smooth or desirable event: “the parents…find it daunting if… you’re supposed to offer them a meeting with the person who conducted the assessment…” (Tom, Administrator). Becky, another administrator further elaborated: “…they’re tired, they’re exhausted. They don’t need another report saying what their kid can’t do…they don’t necessarily want to come in and meet with the psychologist to go over the same thing…”

Breaking down the barriers of intimidation to facilitate open communication between school psychologists, teachers, and caregivers is paramount to information sharing. As it stands, psychologists and other allied professionals are restricted in their time to share information and resources, which can lead to a duplication of services or gaps in service delivery for children with special needs (Reddy & Newman, 2009). This limited sharing of information and resources can leave teachers and caregivers with disjointed assessment results, leading to inappropriate planning and intervention (Reddy & Newman).

Unique to the allied professional group, participants spoke about the need for new and improved teaching strategies as outlined by psychologists within the assessment report: “A lot of the strategies that are given are like ‘Duh’…we already tried that…Some of the strategies are just really silly and stuff that we would already know and…do. We want new and improved strategies that may work [for these students]” (Catia). The specificity of strategies seemed to be of primary concern—with school personnel looking for strategies tailored specifically to the educational needs of children with FASDs. It seems that there is a concern that while the psychologist may be the expert in assessment, he/she may not be an expert on what is happening in the classroom and thus, what interventions would work well for that environment (Knoetze & Vermoter, 2007).

Meaningful understanding. Language used in the report emerged as a key challenge of current assessment practices and was highlighted across teacher, administrator, and allied professional roles. Language that was vague, complex or inconsistent had significant implications for translation of report recommendations into action because school personnel had tremendous difficulty understanding assessment results. For example, one teacher candidly noted that the lack of comprehensible reports leads many teachers to disregard them altogether: "…teachers don't read reports…[except] maybe at [Individualized Program Plan] time…" (Sandra). Given that the psychological report provides such critical information, it is imperative when writing to consider the education level and assessment knowledge of the teachers and caregivers responsible for receiving the information and carrying out suggested recommendations (Anastasi & Urbina, 1997).

Another area of debate was whether reports should include "soft" language (e.g. "delay" rather than "deficit") in describing functional and behavioral limitations. The majority of participants across roles agreed that the use of softer language leads to unrealistic expectations for improvement and pressure on teachers to help children make gains:

> They want us to do assessments every year and see that growth and when they're seeing that their child's not growing then there's got to be blame somewhere…'what is the school doing because my kid is still…[not] progressing?'…[and this is because]… the vocabulary has been very delicate in saying 'there's a delay" and that infers that at

> some point, if you work hard enough…you will catch up… (Sara, Administrator)

Overall, participants spoke to the inaccessibility of report content due to complexities in language and written presentation. This finding is immensely important as it speaks to the continued disconnect between knowledge and action. If teachers and allied professionals are struggling to understand assessment results, the likelihood that related strategies will be incorporated in the classroom is limited. Knoetze and Vermoter (2007) suggest teachers gain familiarity with psychometric tests and psychologists make themselves aware of the aspects of behavioral and cognitive functioning that would be most useful to report on for school personnel and caregivers and write their reports accordingly. Assessment for intervention necessitates a bridging of the gap between the knowledge and skills of school psychologists and those of teachers and allied professionals in terms of assessment so that each stakeholder has a more holistic understanding of the assessment process (Knoetze & Vermoter, 2007) and its ultimate goal of informing intervention.

Implications and Future Directions

This study highlights important implications and serves as a call to action for researchers, school psychologists, and school personnel. In advocating a move toward assessment for intervention, there are 3 main ideas to be emphasized: a) assessment and diagnosis are only as useful as the accommodations and supports that follow; b) the varied learning and behavioral needs of children with FASDs require assessments that are geared toward informing intervention practices in order to achieve the best possible results; and c) support for and inclusion of teachers in the assessment process is vital, recognizing their expertise and value in decision-making for programming and intervention.

The present paper emphasizes the need for a fundamental change in the purpose of assessment. Mastoras and colleagues (2011) report that concerns and complaints about assessment have lingered for more than forty years, and that little progress has been made to improve upon current practices. If school psychologists and educators are to effectively meet the needs of children affected by FASDs, a paradigm shift away from diagnostic and funding goals toward informed interventions must occur. It is in this way that processes can begin to evolve, allowing for greater collaboration among key professionals, improved recommendations, and monitoring of child outcomes. Stakeholders echoed many of the general feelings of dissatisfaction identified in the assessment literature, suggesting that the full potential of assessment is not being realized within the school system. To remedy this, participants suggest a much needed shift in perspective. Through examination of the assessment experiences and attitudes of teachers, administrators, caregivers, and allied professionals involved in working with children with FASDs, it is clear that a responsive assessment process that reflects the whole child can be a valuable catalyst to effective intervention practices.

Assessment must be re-conceptualized as a process of initiating intervention. By using this lens to view assessment, assessment moves beyond simply attaching a diagnosis to a child toward understanding the whole child within their environment in order to best match their needs to the resources available. This perspective then opens the door to some of the needs for teamwork, collaboration, clear communication, use of lay terminology, and consideration of both strengths and deficits of the child with an FASD. This provides the opportunity to approach assessment in a proactive way; thus, avoiding the “wait-to-fail” model and moving toward a “planning-for-success” model. An assessment may or may not result in diagnosis, and yet many affected children require specialized services and supports to succeed in school. The goal then should be to discover and remediate the affected child’s underlying difficulties, using assessment information to inform evidence-based instruction and intervention (Fletcher et al., 2004).

All professionals working with the affected child must be invited to contribute to the assessment at several points, providing understanding and seeking solutions and strategies. By moving to an assessment for intervention framework, a fluid process of informed responding is created that recognizes expertise comes from many places, including both home and school, which may then lead to improved consistency in implementation of recommendations. However, moving to this approach also means that more time must be allotted to teachers and allied professionals to collaborate and plan next steps. Increased recognition of the proactive potential of assessment is also required so responses can be initiated prior to crisis. To enable these changes, it is crucial that both service providers and schools recognize this potential and allocate resources (i.e., time and money). Those involved with the education system must insist on this level of integrated service if this proposed shift is to take place and we are to move forward in assessment and intervention.

Limitations

Due to the special nature of research with FASD populations, several limitations in methodology are noted. First, the use of snowball sampling, while convenient, can produce community bias. Participants are not randomly selected and thus, may affect the representativeness of FASD stakeholders. Those identified have been vocal in the field and may present with more extreme experiences than the average teacher or allied professional working with affected children. A second limitation is the lack of geographical and cultural representativeness of participants in this study since school personnel worked within a single, public school district with children with FASDs of little ethnic variability (e.g., Caucasian or Aboriginal). To address these limitations, researchers tried to select participants from as many different schools and neighborhoods as possible and organized focus group sessions mixing stakeholders to limit the familiarity of participants within each group. Third, the use of focus groups can lead to questions of validity in that participants may be influenced by the researcher and/or other participants, providing responses that will be viewed favorably rather than true experiences (i.e., socially desirability effect). It is believed that providing summaries to participants and allowing them a second opportunity to add to or change their responses helped to enhance the trustworthiness of the data.

Conclusion

Without the fundamental shift toward assessment for intervention, the needs of children with FASDs will continue to remain unmet. The inability to meet the varied needs of this unique population often results in frustration and discouragement for the children and their teachers, and can lead to an alignment with marginalized groups and other disruptive school experiences for the individuals affected by FASDs—all secondary disabilities frequently reported for this population (e.g., Streissguth et al., 2004). Considering the importance of intervention and support services for successful outcomes of children with FASDs, it is imperative that current assessment practices specific to this population be detailed, highlighting key strengths and challenges. The recognition of important strengths and weaknesses in the assessment process helps in the identification of avenues for change as we move toward assessment for intervention with the goal of successful outcomes for affected children.

INTERVENTION

Manuscript Four

Toward better collaboration in the education of students with fetal alcohol spectrum disorders: Integrating the voices of teachers, administrators, caregivers, and allied professionals

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Introduction

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 1 996; 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, and 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 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 and 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 counselor, 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

Table 1. **Focus group and interview questions.**

Objectives	Question	Probes
A) Capturing 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) Identifying 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) Generating evidence-based practices	**Caregivers**: What supports do you use outside the school system have you accessed to help your child? (Academically, socially, behaviourally, emotionally?)	
A) Capturing experiences of key stakeholders	**Caregivers**: Do you know other caregivers in similar situations and how do their experiences compare to your own?	
C) Generating evidence-based practices	**Teachers, Administrators, & Allied Professionals**: Think of a moment when you thought "yes" this strategy is working" with a student 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) Identifying 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 student 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) Identifying areas for future research	**Teachers, Administrators, & Allied Professionals**: What issues are most pressing for a teacher, allied professional, or administrator working with a student with FASD?	
A) Capturing experiences of key stakeholders	**Teachers, Administrators, & Allied Professionals**: What are three adjectives that describe what think about or how you feel when you are told you will have a student with FASD in your school for the year?	
B) Identifying strategies for effective communication	**Teachers, Administrators, & Allied Professionals**: What are your expectations of a student with FASD in the classroom?	

(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.

Data analysis

The analysis was undertaken in three phases: within 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).

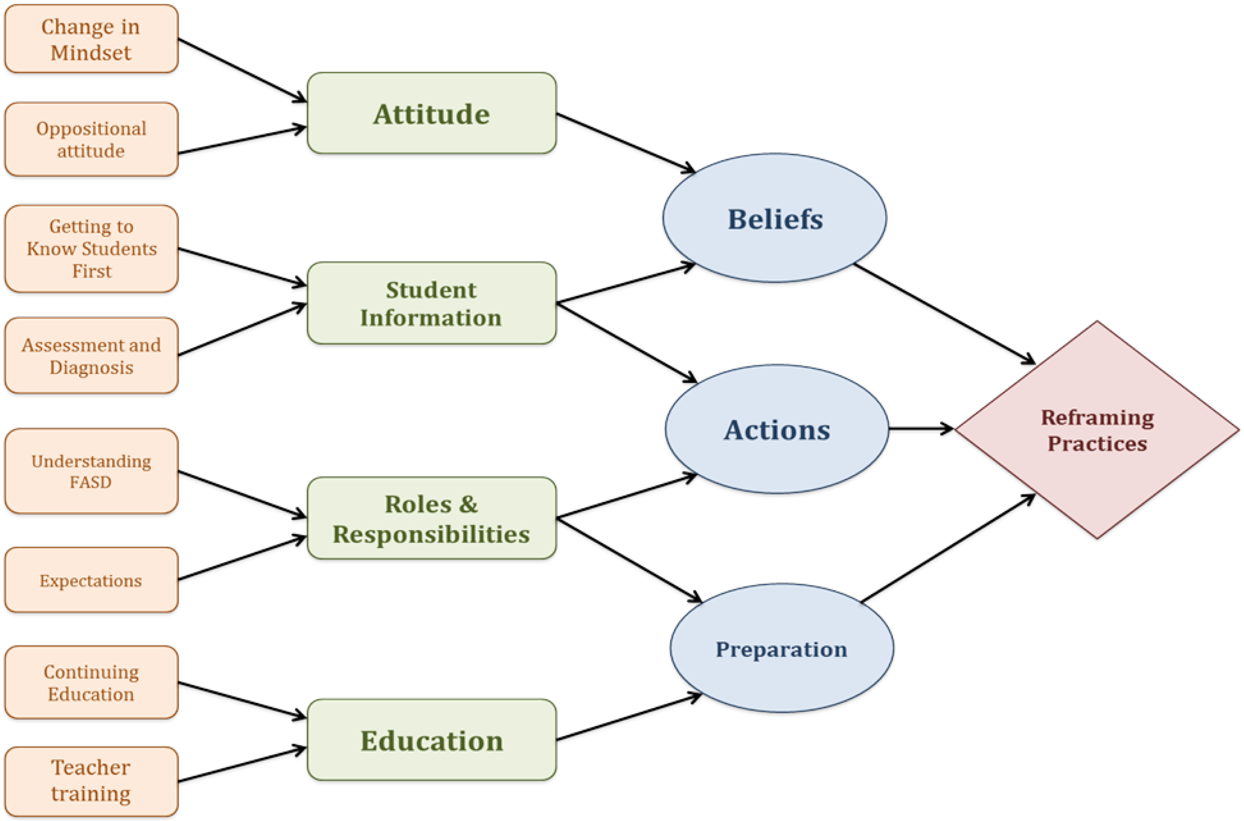

Figure 1. **An example of code and theme development across roles.**

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

Manuscript Five

Toward intentional, reflective, and assimilative classroom practices with students with FASD

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Introduction

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to classify a range of disabilities caused by prenatal alcohol exposure (PAE) including physical, cognitive, emotional, and behavioral deficits (Burd, Klug, Martsolf, & Kerbeshian, 2003; Connor & Streissguth 1996; Kelly, Day, & Streissguth, 2000; Rasmussen, 2005; Pei, Denys, Hughes, & Rasmussen, 2011). The school experience for students with FASD is challenging not only for the student but for all those involved in his or her education including educators (i.e., administrators and teachers), caregivers, and allied professionals (e.g., teaching assistants, psychologists, social workers, and counselors). For children and adolescents with FASD, the school environment can be particularly demanding, as neurodevelopmental damage resulting from PAE greatly impacts behavioral and cognitive functioning (Koren, Nulman, Chudley, & Loocke, 2003). The cognitive deficits associated with FASD (e.g., weak memory retention, limitations in abstract reasoning, and poor information transfer) have significant effects on the student's learning and achievement (Duquette, Stodel, Fullarton & Hagglund, 2006b; Rasmussen & Bisanz, 2006). Equally challenging are the social and emotional impairments associated with FASD (e.g., emotional outbursts, poor empathy, and a narrow social conscience), which have been shown to significantly hinder a student's ability to form positive and appropriate relationships with peers and teachers (Kalberg & Buckley, 2007; Roebuck, Mattson & Riley, 1999). Given these struggles, it is not surprising that up to 60% of students with FASD will experience some disruption to their education (e.g., suspension, expulsion, or drop out) before the age of 18 (Streissguth, 1997). Efforts from educators, caregivers, and allied professionals are key to decreasing these disruptions and ensuring that students with FASD receive the education and care needed to lead high quality lives (Green, 2007; Ryan & Ferguson, 2006a). However, it remains uncertain what strategies and classroom practices are effective for guiding these efforts.

The literature has highlighted a number of factors associated with successful educational experiences for students with FASD including a welcoming environment, willful administration, adequate resources, and knowledgeable teachers (Brownell & Pajares, 1999; Cook, Tankersley, Cook, & Landrum, 2000; Federico, Herrold & Venn, 1999). Specifically impactful are teachers who can adapt classroom practices to respond to diverse student needs, yet many teachers report being limited by a lack of knowledge about the complex learning, social, and behavioral difficulties of students with FASD. Thus, these teachers are often challenged to understand and effectively respond to the learning needs of students with FASD (Blackburn, 2009). Limited professional learning opportunities lead to a dearth of critical knowledge and skills for guiding appropriate educational programming (Carpenter, 2011).

The need for further professional learning opportunities for teachers is underscored by recent findings from the United Kingdom (UK), Canada, and the United States (US). Multiple UK-based studies reveal startlingly limited FASD awareness and knowledge among educators (e.g., Blackburn, 2009; Blackburn, Carpenter, & Egerton, 2010). In a study of 161 early childhood practitioners, 78% reported little to no knowledge about FASD and maternal alcohol consumption, a noteworthy finding given that 40% of early education settings in the UK include students with FASD (Blackburn, 2009). Similarly, a recent survey involving 77 pre-service Canadian teachers revealed a limited understanding of the causes and learning challenges of students with FASD leading to misinformed assumptions (Pei, Job, Poth, O’Brien-Langer, & Tang, 2012). The study further highlighted the focus of initial teacher education on the observed behavioral difficulties rather than the underlying cognitive and learning deficits of students with FASD. This finding is important because it may reflect use of strategies that fail to address the core needs of the child as well as observed difficulties (Pei et al., 2013).

While the majority of literature focuses on general teacher preparation, a US study focusing on the initial preparation of special educators and speech-language pathologists working with students affected by PAE found a significant need for greater knowledge and skill-building in applying strategies to effectively assist student difficulties (Watson, Gable, & Tonelson, 2003). The message is clear: improved awareness and education is imperative if educators and allied professionals are to understand and respond to the unique needs of students with FASD in ways that allow these students to maximize their potential and achieve educational, social, and behavioral goals (Blackburn et al., 2010). In seeking to integrate students with FASD and other complex needs into the classroom, generation of strategies will require an understanding of the environmental influences that shape students with and without FASD. This understanding is paramount to developing collaborative working relationships between caregivers and school personnel, which then enables development of interventions that center on holistic and systemic change (Rogers-Adkinson & Stuart, 2007).

Ecological systems theory emphasizes the manifold, interconnected environmental systems in which students develop (Bronfenbrenner, 1979). The most important ecologies in this context are “systems” of direct relationships between students with FASD and caring adults including caregivers and teachers. In ecological systems theory, three of the five layers described (Bronfenbrenner, 1979) are pertinent for informing this study. These layers refer to different contexts that influence the learning environment, and are important for the teacher in understanding his/her potential role. Examples of how this theory applies to an FASD population are put forth. The first layer, the *microsystem*, contains the places and people that are within a student's immediate environment such as the family and school. For example, the immediate family including siblings and caregivers of a student with FASD and members of the student's school community contribute to their home-school relationships and experiences. The second layer is referred to as the *mesosystem* and includes the interrelations of two or more microsystems in which the developing student learns and grows. For example, the relationship between caregivers and teachers of a student with FASD is relevant at the mesosystem level as it affects the caregiver's decision to use teacher-recommended learning strategies when helping with homework. The *exosystem* is the third layer and involves connections between a social setting in which the student does not have an active role in his or her immediate context (Bronfenbrenner, 1979). For instance, the child welfare system could be considered part of the exosystem of a student with FASD because of the high number of foster, adoptive, and institutional care situations in this population (Barth, 2001). This system is a context that is external to the student and his or her family but affects them through determining custody arrangements (Rogers-Adkinson & Stuart, 2007).

It is important for teachers to recognize that communication and collaboration among the three levels of systems is vital in providing a quality educational experience for the student with FASD. Although caregivers can help with advocacy and modeling, school personnel and allied professionals have influence by creating and following individual education plans (IEP), establishing smooth transition plans, and collaborating with caregivers (Duquette, Stodel, Fullarton, & Hagglund, 2006a). Therefore, it may serve schools to consider how skill-building opportunities that facilitate effective collaboration between home and school might be integrated into initial teacher preparation. One study that integrated caregiver interaction in educational programming enabled pre-service teachers to see the benefits of including caregivers in the development of individualized interventions, respecting caregivers' expert knowledge of the child (Murray, Curran, & Zellers, 2008). In a similar vein, Canadian researchers found that the fostering of positive working relationships between caregivers, school personnel, and allied professionals led to the formation of personal and professional beliefs based on accurate and sound information and improved care across settings (Job et al., 2013). These studies lead us to reflect on the tremendous value the caregiver can add to a child's education, especially where complex needs are concerned. This underscores the importance of communication between the family, school, and community systems in decision-making about educational programming (Rogers-Adkinson & Stuart, 2007).

Moreover, the paucity of research examining effective classroom strategies for students with disabilities and specifically with FASD is striking given the well-documented myriad of educational challenges and importance of early intervention (Kodituwakku & Kodituwakku, 2011; Ryan & Ferguson, 2006a). Yet research to date has failed to integrate findings to inform such strategies. For example, some researchers have highlighted the importance of addressing the self-worth and identity of students with disabilities through mentoring and conversation with trusted adults as well as engagement in personally meaningful activities that facilitate self-awareness and independence (Benz, Lindstrom, & Yovanoff, 2000; Lindstrom et al., 2007). Other research related specifically to students with FASD have emphasized the students' learning and achievement difficulties as most important, specifying intervention efforts geared toward more educationally-related goals including helping students to understand rules, transition between different environments, and use feedback to create new learning habits (Green, 2007). By integrating differing perspectives on what constitutes promising classroom practices, this study aims to generate a more holistic guiding framework for teaching and intervention.

The school setting is a place where the unique set of challenges experienced by students with FASD is evident (Green, 2007), thus it seemed logical to begin with an exploratory study involving those who work most closely with these students in this context (e.g., teachers and administrators). In addition, caregivers and allied professionals were included in this study because of their potential to provide invaluable insight into how educational practices translate and influence the home and community systems. Each student with FASD brings unique thoughts, feelings, aspirations, interests, and talents to the learning process. The effort to recognize and cultivate these attributes is critical to the development and implementation of successful strategies and interventions. The purpose of the present study was to unite diverse beliefs about the learning and developmental needs of students with FASD.

The exploration of experiences and influences of classroom practices for students with FASD is part of a larger program of research focused on improving assessment and intervention for these students (e.g., Pei, Job, Poth, & Atkinson, 2013). Of particular importance to the present study was capturing a rich description of the collaborative efforts to understand and overcome the developmental, learning, and behavioral challenges of students with FASD from multiple perspectives. Thus, to be able to inform student programming that follows a holistic approach to education, this study documents the experiences of teachers, administrators, caregivers, and allied professionals and influence of different systems in the education of students with FASD and then identifies influential teaching strategies for meeting the learning and developmental needs of students with FASD.

Methods

A qualitative approach was appropriate for generating rich descriptions, given the focus of the study to explore the multiple experiences and perspectives of those working with students with FASD, with the aim of identifying effective classroom practices (Creswell, 2013). Specifically, the choice of focus groups as a suitable method of data collection was based on the desire for facilitated discussions around a specific topic, that is, experiences of working with students with FASD (Krueger & Casey, 2000). A distinct advantage of a focus group is its effectiveness in collecting rich qualitative data in a short amount of time, giving access to observing the interactions among participants, and providing opportunities for participants to build upon each other's responses (Creswell, 2008). For those participants who were not able to attend a scheduled focus group, an individual semi-structured interview was offered as an alternative option. 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 having a degree of expertise in special education, a mean of 13.2 years of experience (range 1-32 years), and representing all levels of instruction (7 identified as Kindergarten to Grade 5, whereas 24 identified as Grades 6 to 12). Administrators had a mean of 22 years of experience (range 15-30 years) and various roles (2 principals, 4 assistant principals, and 1 head of student services). Allied professionals reported a mean of 10.9 years of experience (range 1-25 years), with the majority ($n = 12$) identifying their roles as educational assistants and the remaining as "other" (i.e., in-home consultant, reading specialist, guidance counselor, and manager of the school's Academy of Reading & Math Programs). Caregivers consisted of 2 maternal grandmothers, 3 foster mothers, and 1 adoptive mother. Caregiver years of experience ranged from 6 to 43 with a mean of 17.8 years. The age range for children with FASD with whom the stakeholders worked was 3 to 18 years with a mean age of 12.4 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 teachers were required to meet all of the following inclusion criteria: (a) experience with a student with FASD; (b) involvement in that student's psycho-educational 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 were held with a mean number of six participants grouped according to role and three individual interviews involving one administrator and two caregivers. Each session lasted approximately one hour and followed a semi-structured protocol of eight questions 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. Two research assistants (a moderator and a note-taker) with advanced training in qualitative research methods and analysis facilitated and audio-recorded each focus group or interview. Following each of the sessions, the research assistants debriefed with each other to capture in field notes the atmosphere of the discussion as well as the issues and concerns that had emerged unprompted. The conversations were then transcribed verbatim, and a preliminary analysis generated summaries that were electronically distributed to participants as a means of member checking. Subsequent participant feedback and additional comments were incorporated into the transcriptions to ensure accuracy of the data and completeness of participant responses.

Data Analysis

The analysis was undertaken in two iterative phases to allow for three types of comparisons across individual focus groups, same-role focus groups (e.g., teachers, administrators), and different-role focus groups (e.g., teachers vs. caregivers, allied professionals vs. administrators). First, two independent researchers for the same transcript inductively generated codes and compared similarities and differences between the code lists. Once consensus related to definitions and examples was reached, the code definitions were used on a second transcript and an inter-rater reliability of 90% was sought and achieved. The code definitions were then applied across all the transcripts and summaries for each role to highlight similarities within and differences across roles (see Figure 1).

To ensure the inductive process captured all ideas across roles, a second deductive analysis process was undertaken whereby the two researchers read each transcript independently focusing on each of the protocol questions (e.g., the code *expectations* emerged in part from, *"What are your expectations of a student with an FASD in the classroom?"*). These findings were compared with issues and concerns gathered from the research assistants' post-session field notes. Taken together, the deductive analysis allowed for more comprehensive understanding and further streamlining of the themes generated by the inductive analysis. Finally, a third

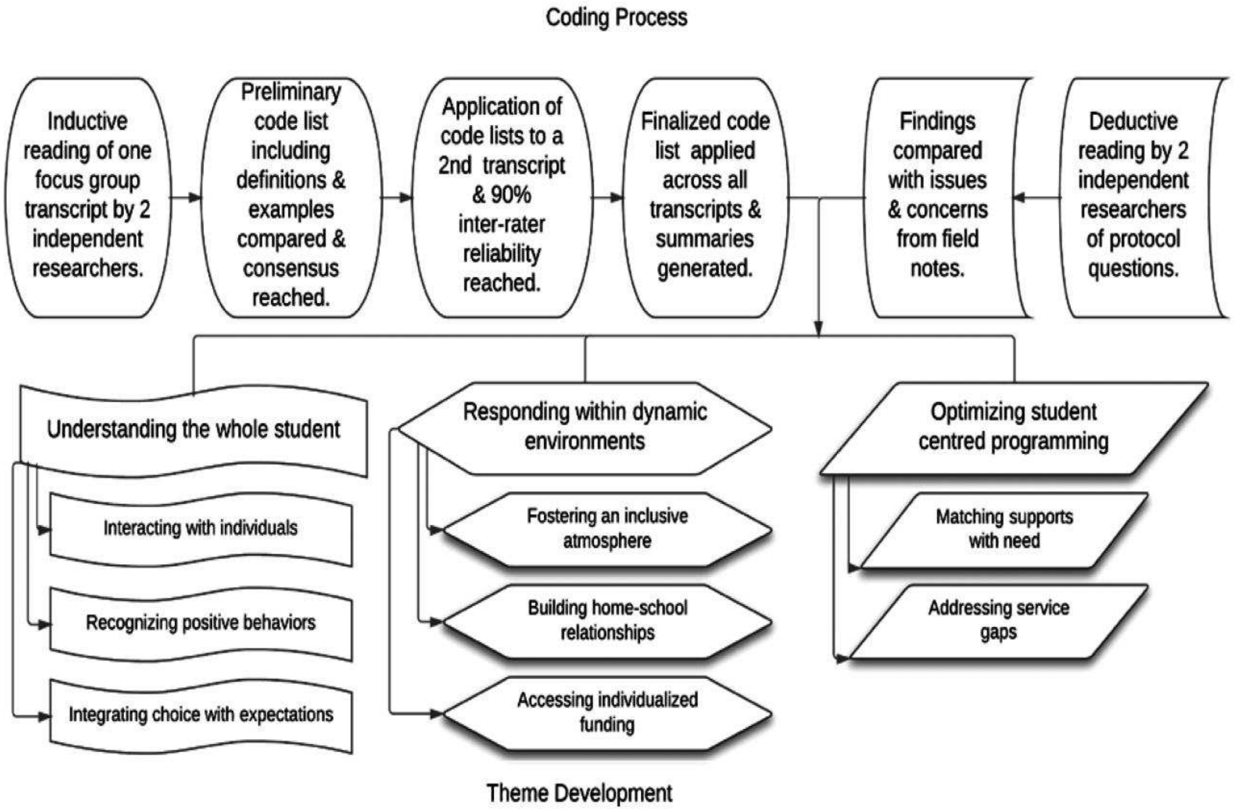

Figure 1. **Summary of coding process and theme development involved in data analysis.**

researcher reviewed the analysis procedures and confirmability (i.e., the degree to which the themes were grounded in the data) and dependability of the data was discussed as a group (Lincoln & Guba, 1985).

Findings and Discussion

By employing a holistic lens, integrating multiple perspectives, to the present study it was possible to generate a more comprehensive understanding of student programming that follows a holistic approach to education. In so doing, we build upon existing research on the educational and behavioral challenges of the FASD student population to forward successful strategies and interventions. The analysis of the data begins to address the study's purpose to unite diverse beliefs about the learning and developmental needs of students with FASD in its generation of three overarching themes: *understanding the whole student, responding within dynamic environments,* and *optimizing student-centered programming*, which lend considerable support for a holistic approach in the education of students with FASD and provide direction for teacher education and professional development. The following section is organized by each theme and subthemes to identify influential classroom strategies.

Understanding the Whole Student

The investment of time with the aim of getting to know students on a personal level rather than relying on external reports is the focus of the first theme. To gain an understanding of the whole student, educators, caregivers, and allied professionals encouraged individual interactions between teachers and students to minimize pre-conceived assumptions, recognize positive behaviors to encourage future actions, and integrate choice with expectations in order to encourage students to see themselves as decision-makers. These strategies were perceived as foundational to the progression involved in student identity development and transition to adulthood.

Interacting with individuals. Both teacher and allied professional groups identified individual interactions with students as having a major impact on building effective relationships. For one teacher, Callie, getting to know students allowed her to provide an individualized approach saying, “it is all about building relationships with kids…understanding their limitations or their strengths and what they are capable of really on an individual basis…” Familiarity with students’ individual triggers better positions teachers for proactively managing behavioral difficulties as Sandra (Teacher) explained:

> …as soon as they walk in the door…[it’s important to discover]…who’s in what kind of a mood…and which ones you can get to work hard [versus those who] are going to flip

> out on you if you push their button…

To that end, an individualized teaching approach may be more effective when contrasted with a homogeneous approach based on pre-conceived notions or understanding of FASD. These findings point to the successes associated with this approach and are consistent with previous research wherein teachers relay the importance of remembering that students with FASD are individuals with unique interests and talents (Ryan, 2006; Ryan & Ferguson, 2006b).

For allied professionals, the key concern was getting to know students before reading their cumulative records (i.e., a compilation of information regarding a student's academic progress, mid-term and final marks, adaptations and attendance). This was important because of the potential influence that such a record may have on a professional's view of a student prior to working with him or her: "…some of the stuff that you read is very negative…and whether you think it will or not, it does [matter]. It's in the back of your mind…" (Daria, Allied Professional). Indeed, there was considerable agreement across participants that much of the information contained within cumulative records is more likely to be deficit-related and unconstructive in terms of highlighting student strengths. Bob, an allied professional, expressed a similar view, and the described the potential implications of having pre-conceived ideas prior to interacting with the student with FASD:

> I don't…want to look at [cumulative files] because so much of it is…negative… sometimes I think what is in [cumulative files] is in support of maintaining funding rather than being a clear picture of [who] this child is…[with] a lot of kids I have worked with, we would not have had nearly so much success…had [I] read the [cumulative file] first.

These findings point to concerns on the part of allied professionals to access cumulative records prior to interacting with students because of the potential for information contained within the files to influence how they view students' potential. This idea aligns with research in the identity literature suggesting that making assumptions about the skills and abilities of students with FASD based on general knowledge or previous reports can be detrimental to student self-efficacy and achievement—two aspects that are key to the development of a healthy identity and successful educational outcomes (Lindstrom et al., 2007). If school personnel and allied professionals focus on the person rather than the disability, it will be easier to help students with FASD identify their own values, needs, capabilities, and interests, and develop a more positive sense of self and others (Lindstrom et al., 2007; Ryan & Ferguson, 2006b).

Recognizing positive behaviors. Participants highlighted the importance of practices focused on building students' positive assets rather than focusing on negative characteristics. As one participant commented, "these kids get in trouble so much of the time that…if I…see them being good I try to do something with that" (Bob, Allied Professional). Becky, an administrator, agreed that it is imperative to "…recogniz[e] the positive behavior and reinforc[e] [it]." These findings are not surprising given literature that details the social struggles experienced by students with FASD due to limitations in impulse control, planning, and judgment, which lead to inappropriate behaviors (Burgess & Streissguth, 1992). Positive asset building can be accomplished at home and school, through both acknowledgment of positive behavior and providing opportunities for involvement in helpful, productive activities:

> …another thing that I've seen is that a lot of foster parents and direct caregivers do that has made a huge difference for a lot of the kids is positive asset building. They identify interests early and they get them involved in those things…leadership opportunities…part-time work and work experience… (Hailey, Allied Professional).

The academic and behavioral challenges of students with FASD can be so profound that it is sometimes difficult to recognize strengths or encourage positive behaviors when they are demonstrated (Ryan & Ferguson, 2006b). For this reason, it is crucial for each stakeholder to examine his or her contribution to the education of students with FASD and work to promote healthy identity development. With an emphasis on positive behaviors and collaborative interventions that focus on holistic change, it is believed that school personnel and allied professionals will be able to make lasting positive impacts in the lives of students with FASD (Rogers-Adkinson & Stuart, 2007).

Integrating choice with expectations. Participants across roles noted several key responsibilities of school personnel and caregivers including offering students choice within consistent expectations. Allowing students with FASD liberties to be who they are helps to build their personal identity. As Katie, an allied professional, shared:

> I…allow them to make choices for themselves within a confined boundary of what those choices can be and they tend to actually really like the idea that they're making their own choices. I don't ever like to take their choices away from them. So, I try to direct them to choices that they're able to have…and any time we see anything that's positive to mention it…

Previous researchers have emphasized the benefit of affording students some degree of control over their decision-making by providing choice. In a qualitative study exploring transitional resources for students with disabilities, one participant noted the value of creating an agenda with the student that emphasizes choice and options. It allows that student "to feel the power that comes with being independent and making your own choices" (Lindstrom et al., 2007, p. 11).

Darlene, a caregiver, also noted her desire to have teachers and allied professionals maintain consistency in expectation despite her son's learning limitations. In this way, the student with FASD is included in the class and encouraged to work through challenges and failures, building up his confidence and skills:

> …my five year old is very, very delayed…but I let [the teachers] know that he's not coming [to school] to play…He will be expected to do what the other kids are doing…and if he can't then he has to make an attempt…I know what he's capable of, so we need to push him…because then [he] can reach [his] full potential.

Additional research involving school personnel, adults with disabilities, and employers has identified several strategies helpful in preparing students with disabilities for the transition to adulthood including involvement in individualized programming and meaningful activity focused on developing self-awareness and independence (Benz et al., 2000; Lindstrom et al., 2007). Based on this research and the current findings, it seems that providing students with FASD the opportunity to practice autonomous decision-making and encouraging positive behaviors enhances the likelihood that these students will be equipped for life beyond school.

Responding Within Dynamic Environments

The focus of the second theme aligns with Bronfenbrenner's (1979) ecological systems theory; that is, the influence of different environments on student development, learning, and achievement. To be able to respond within these dynamic environments, educators, caregivers, and allied professionals paid attention to how the three independent systems (i.e., school, home, and government) influenced their work with students with FASD. Specifically of interest was whether the school fostered an inclusive atmosphere that welcomed students and caregivers, how developing home-school relationships provided consistency for students, and how accessing individualized funding provided early supports. These strategies were perceived as important for providing information that supported the educational experiences of students with FASD.

Fostering an inclusive atmosphere. The way in which a school operates and how classrooms are managed emerged as an influential microsystem for students with FASD. Chloe, a caregiver, recounted her experience enrolling her son in kindergarten:

> …as soon as we mention FAS, right away [the principal says], "well, I don't even think he's in our school zone. I better check…" She didn't want him in that school. She look[ed] to verify that he was in the correct boundaries and then…[tried] to convince us that maybe they didn't have the right programming for him and that [we] should go to a special needs school.

Participants across roles spoke to the need for inclusive school and classroom environments wherein students with FASD and their families are welcomed and supported. Despite this consensus, caregivers and administrators alike acknowledged that there remains a resistance to including students with FASD in classrooms due to a lack of awareness of the needs of these students and professional opportunities to learn about effective strategies. This sentiment is consistent with research that shows greater opposition with regard to enrollment and accommodations from schools where the administration and teaching staff are unfamiliar with the disorder (Duquette et al., 2006b).

Building home-school relationships. The strength of relationships between home and school emerged as a central mesosystem involved in setting up students with FASD for success. Teachers and allied professionals alike stated that successful outcomes for students with FASD are largely dependent on the teacher-student relationship, and that trust between those involved in the students' home and school environments is imperative for promoting consistent educational and behavioral practices across settings. Caregivers pointed to the need for students with FASD to see caregivers and teachers as working together to reinforce consistent practices:

> I want the school to work with me because with FASD kids, consistency is the key [across domains]…because a lot of kids think that school and home are separate and that mom doesn't know what goes on in the school and school doesn't know what goes on at home… (Darlene, Caregiver).

Although educators and allied professionals in the present study recognized the value and potential for developing relationships with families, they noted the need for sensitivity to the barriers and challenges associated with raising a child with FASD. One teacher, Brad, described his perception of the tremendous effects of the lack of a home-school relationship on academic routine and achievement: "There are times that it would be nice almost if there wasn't a weekend...[the] continuity gets broken…[and] I find we lose [progress] over the breaks and on the weekends..." In the same way, Chloe, a caregiver noted the negative consequences of one attempt to speak with her child's principal where she was met with unresponsiveness and apathy: "The principal…is someone who…runs his own ship…we don't have much of a rapport with him. When I did try to talk to him, his answer was if we weren't happy we could [change schools]…" Other caregivers expressed similar experiences wherein they were concerned that their voices would not be heard and that educators would not appropriately consider the unique needs of their children.

The contribution of bidirectional efforts for developing trust is highlighted by these findings. Specifically, literature clearly establishes the need for increased partnership between families and educators and allied professionals as well as the desire for reliable relationships with teachers and administrators from the caregivers' perspective (e.g., Ryan & Ferguson, 2006b) yet the impact on increasing consistency must be given significant consideration. Thus, it is not surprising that previous conversations with families of students with FASD have revealed that caregivers report feeling overwhelmed by the challenging behaviors of their child and frustrated by the lack of specialized community and school resources (Ryan & Ferguson, 2006a; Job et al., 2013). The pervasive and taxing nature of FASD, together with the absence of services, has been shown to greatly impact a family's relationships, social networks, and daily activities (Fox, Vaughn, Wyatte, & Dunlap, 2002). Research also clearly demonstrates that a stable home environment can serve as a protective factor for students with FASD. However, creating this home environment and advocating for needed services often require more time and effort than caregivers are able to give (Carmichael-Olson, Rudo-Stern, & Gendler, 2011). Therefore, any additional advocacy or support that educators or allied professionals can provide may greatly improve consistency in educational and behavioral strategies across home and school.

Accessing individualized funding. The level of individualized support school personnel are able to provide is greatly influenced by the financial resources for services within school districts and individual schools allocated by the exosystem involving government policy. Not surprising, access to services such as psychoeducational assessment, speech and language therapy, and occupational therapy are based on whether the student with FASD qualifies for funding. What became apparent in this study was the positive impact of early access to such services on the student's learning environment. In some instances, caregivers report that the experience of assessment and diagnosis led to valuable support that would have been otherwise inaccessible:

> …our grandson was given two years [of funding] in kindergarten and he had occupational therapists and physiotherapists [in the classroom] because he was eligible for it...[as well we had] someone coming to the house to work with him…so everything was really good but it was all based on that diagnosis. (Laura, Caregiver)

However, not all experiences accessing services were so encouraging. As Tom, an administrator noted, some aspects of the assessment process can be quite difficult including significant wait times and poor caregiver advocacy:

> …sometimes the family has challenges of their own so they don't always recognize…that they need to take some extra steps to get help for their child…if their circumstances aren't the greatest, you can give them all the information to get to the supports but they don't necessarily make it…

If the goal is to provide quality education and support for all students then this study points to the need for early access to assessment and diagnosis. Researchers (e.g., Ryan & Ferguson, 2006a) remain hopeful that continued study of challenging behaviors, positive behavioral supports, and coordinated systems of support for students with FASD will aid in transcending current government and school district policies to increase early assessment for this often overlooked population, and encourage stakeholders to employ suitable strategies for intervening effectively with students with FASD and their families (OMHSAS Bureau of Children's Behavioral Health Services, 2011).

Optimizing Student-Centered Programming

Maximizing opportunities for student-centered programming that meets the individual needs of students with FASD is highlighted as the final theme across groups. In order to create student-centered programming, educators, caregivers, and allied professionals must be open to adapting programming in response to available resources as well as advocating for more support where needed. Specifically, this theme included classroom strategies designed to provide students with FASD the specialized programming they need to be successful by matching learning supports and addressing gaps in service.

Matching supports with need. The ability to successfully match learning supports with need is based on the shared view of the importance of individualized programming for students with FASD. The majority of participants spoke to the need for a structured learning environment with consistent leadership, rules, routines, and consequences for behavior: "…kids need to know who's in charge. They need to know they're safe and the way that they know that is by setting limits and consequences" (Darlene, Caregiver). Participants also acknowledged that teaching a student with FASD is challenging in any setting: "…it's hard because everything is concrete with a child [with FASD] and everything has to be consistent…and structured" (Chloe, Caregiver). Some settings, in particular, were described as effective for meeting individual students' learning needs:

> …the thing coming [to a school for students with cognitive and educational disabilities] is the level of programming that we can offer and the [activities]…the kids can be involved in. It's more life-skills oriented…there's a lot of hands-on [learning]…that is going to be meaningful to them. (Bryan, Administrator)

A perception common across all roles was the necessity of intensive and specialized instruction emphasizing the development of academic skills and personal characteristics:

> I think intensive programming is necessary initially to give them some strategies and some good self-concept feelings and then maybe slowly try to wean as they adjust to school and they've built that confidence…to assist themselves more than anything. (Wynne, Administrator)

These findings align with those of a recent investigation supporting the use of targeted instructional strategies for students with FASD (O'Connor et al., 2006) as well as interventions that promote behavioral reframing and environmental accommodations (Olson et al., 2005;

Jirikowic et al., 2010). This signifies an emerging trend in conversations with stakeholders involved in the education and care of students with FASD—highlighting the importance of supporting not only academic learning but also the development of confidence and identity among these students so that they may achieve successful outcomes beyond the classroom (Rogers-Adkinson & Stuart, 2007). It is essential for educators and allied professionals to possess knowledge of the needs of individual students and to consider a variety of educational and behavioral strategies in their work with students with FASD.

Addressing service gaps. More effective collaboration among school- and community-based services is necessary for increased access to assessment and effective transition to adulthood. Allied professionals and administrators remarked that some progress has been made with school and children's services beginning to acknowledge gaps in community support yet struggling with a need for more resources: "We…need to bring in a lot of outside support for students who have FAS[D] because they don't always make those connections…you have to provide mental health support…" (Tom, Administrator) and "informal supports [within the] community…" (Hailey, Allied Professional). In particular, participants agreed that some classroom strategies such as smaller class sizes and a greater focus on vocational skills, especially at the high school level, would aid in preparing students with FASD for life beyond the classroom: "Basic literacy if they get it…but more vocational and life skills" (Larry, Teacher).

Researchers (e.g., Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008; Duquette et al., 2006b; Watson & Westby, 2003) echo participants' emphasis on the importance of specialized services for students with FASD within the classroom as well as in transition to work and independent living. Specifically, the work of Lindstrom and colleagues (2007) highlighted the need for an individualized approach offering multiple opportunities for students with FASD to learn from challenges and successes as they prepare for adult roles and responsibilities. One of the remaining challenges is limited awareness of FASD among community-based services. A collaborative approach to educate community organizations about the condition in order to obtain suitable resources is crucial to effecting positive change (Caley, Kramer, & Robinson, 2005).

Implications

The importance of this study for teacher education and professional development is two-fold: (a) FASD now outranks Autism and Down Syndrome in prevalence (The Substance Abuse and Mental Health Services Administration [SAMHSA], 2005; MoFAS, 2010) and (b) students with FASD typically receive instruction in general education classroom settings (Ryan & Ferguson, 2006a). Thus, the likelihood of a having a student with an FASD is high, and teachers need to be prepared. Researchers have been divided in their views of how teachers should approach education with this special student population. Many have concentrated on learning and achievement, gearing intervention ideas toward behavioral and educational and goals (Green, 2007; Dybdahl & Ryan, 2009). In contrast, some authors speak to the emotional and psychological health of students, highlighting the development of self-worth, emotional regulation, and personal identity as key to student success (Benz, Lindstrom, & Yovanoff, 2000; Lindstrom et al., 2007). The present study combines both perspectives and suggests a holistic framework that emphasizes developmentally appropriate practice wherein the teacher nurtures a student's social, emotional, physical, and cognitive development (Kochhar-Bryant, 2010). This approach to classroom practice expresses an *ecological consciousness*—recognizing that everything in the world exists in context, and that the diversity of students with FASD should be embraced and cultivated.

Taken together, the study findings support an overarching framework to classroom practice that is intentional, reflective, and assimilative, and to professional learning opportunities that are grounded in classroom-based research. This approach bridges all three themes suggesting positive outcomes are achieved through classroom strategies that gain an understanding of the whole student, respond appropriately to the dynamic influences on the student's complex environments, and maximize programming that supports the student's learning and development. To be intentional is to use actions that are chosen based on an understanding of the complex needs of the student with FASD, the environment within which the student functions, and the supports necessary for optimizing programming to achieve desired learning and development goals. Reflective practice then requires engagement in thinking processes to evaluate actions, determine the extent to which desired goals were achieved, and consider the potential reasons for the observed outcomes. Finally, to be assimilative entails responding to the new ideas and learning gained through reflection so that future action may be shaped by experiences. These three actions – intention, reflection, and assimilation – enable teachers to respond to complex student needs, dynamic environmental influences, and variable support allocation in ways that are both innovative and adaptive.

There are three implications for developing professional learning opportunities reflective of an approach incorporating the iterative processes of intentional actions, reflective thinking, and assimilation of ideas (see Figure 2). The first is the need for teachers to reconceptualize their classroom practices as evolutionary that is viewed as a constant progression of adaptation. To this end, teachers respond to students in their classroom in a way that is not constrained by rules or routine but rather as part of an evolutionary process that can inform and improve classroom

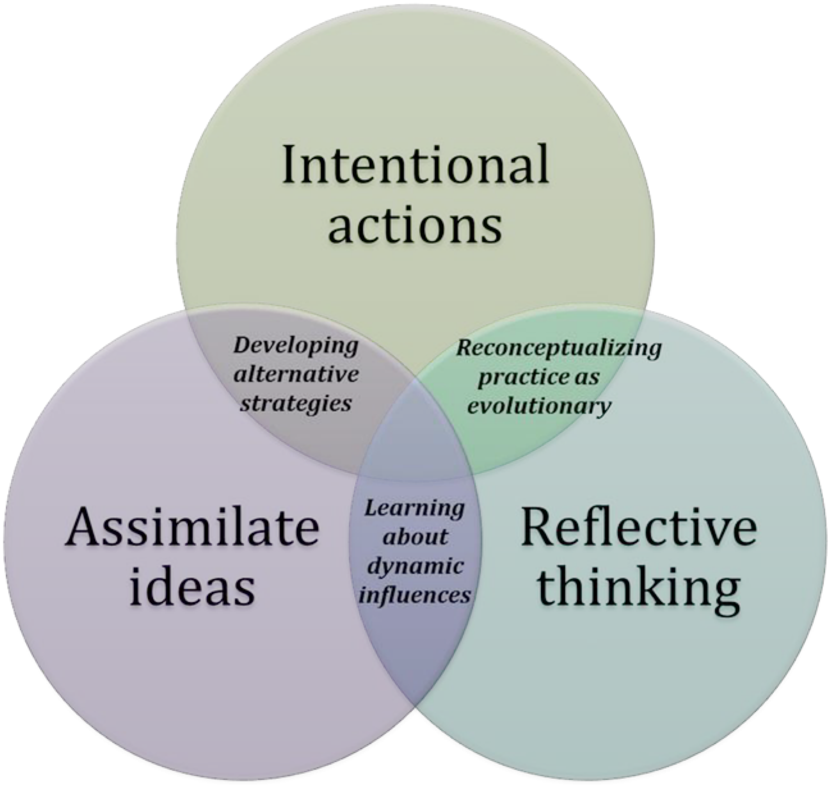

Figure 2. **Visual representation of the three iterative processes and implications of the approach involving intentionality, reflection, and assimilation.**

practice for all children. Second is the need for monitoring students' dynamic environments, which can greatly influence their potential academic outcomes. To this end, teachers learn about how the classroom, school, home, and broader systems affect each student, which better positions the teacher to meet individual learning needs. The final implication relates to the need for alternative strategies and novel programming in a low-risk environment wherein teachers engage in trial and error teaching and programming, reflect upon successful and unsuccessful practices, and communicate openly with others to explore what may be done differently to establish a shared understanding of the needs and strengths of students with FASD.

In order to capture the experiences and perspectives of those involved in the education of students with FASD, focus groups and interviews were conducted. This can be considered both a limitation and a strength of the present study because they are limited to what participants are willing and able to articulate within a group setting; however, all possible measures were taken (e.g., grouping by role, beginning with low-risk questions) to provide a comfortable atmosphere for sharing, and it is believed that participants were forthright and honest. Evidence of this was provided through detailed answers and field notes indicating observations that participants were engaged and often stayed after the sessions were completed to converse further. Finally, the focus on individuals involved in the education of students with FASD provided a comprehensive understanding of the experiences of only this specific population, however the findings remain relevant for other students with complex needs as well. Further research is recommended to (a) address the limitations highlighted within these findings and to (b) replicate this study across populations for greater generalization and understanding of how an approach characterized by intentionality, reflection, and assimilation could enhance classroom practices beyond the FASD population for additional complex student populations.

Conclusion

By documenting experiences and identifying influential classroom strategies, this study provides an essential step toward better-prepared educators and allied professionals for meeting diverse learning and developmental needs of students with FASD as well as additional complex student populations. The study highlights the untapped potential for evidence-based practices to inform the expansion of professional learning opportunities for educators by forwarding an approach characterized by intentionality, reflection, and assimilation. This research was not about identifying a set of rules for working with students with FASD but rather about establishing a basic philosophy of positive interaction and understanding of the core developmental needs of children with complex presentations. The hope is that once established, this philosophy may lead to changes in the way we interact with all students in order to increase their chances of successful outcomes.

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CHAPTER IV

DISCUSSION

For more than 30 years, pregnant women and women who are considering pregnancy have been advised about the dangers of prenatal drinking. In 1981, a public health advisory from the Office of the Surgeon General warned women to *limit* their alcohol intake during pregnancy (Food and Drug Administration [FDA], 1981), and an update in 2005 urged pregnant women and women of childbearing age to *abstain* from drinking alcohol (CDC, 2005). This advisory also urged healthcare professionals to include questions of alcohol consumption in examinations and routine visits and educate patients about the risks of drinking while pregnant. As well, numerous studies have been published, detailing the very real link between PAE and fetal brain damage, growth retardation, and other adverse pregnancy and birth outcomes (e.g., miscarriage, preterm birth, low birth weight, sudden infant death syndrome) (Aliyu et al., 2008; Athanasakis, Karavasiliadou, & Styliadis, 2011; Bailey & Sokol, 2011; Iyasu et al., 2002; Meyer-Leu, Lemola, Daeppen, Deriaz, & Gerber, 2011; Kesmodel, Olson, & Secher, 2000); and still, women continue to consume alcohol during pregnancy.

A recent survey by SAMHSA (2014) revealed disconcerting information about alcohol use in pregnancy. Among pregnant women aged 15 to 44, an annual average of 9.4% reported current alcohol use, 2.3% reported binge drinking (5 or more drinks within a short time period), and 0.4% reported heavy drinking. Further, 19% of pregnant women reported at least some consumption of alcohol during their first trimester—a critical period for fetal development and yet, a time when many women may not be aware they are pregnant. Additionally, 6.6% reported engagement in at least one episode of binge drinking during their first trimester, which may be especially harmful to the developing fetus (SAHMSA, 2013). These statistics are akin to those found a decade ago (SAHMSA, 2004; Walker, Al-Sahab, Islam, & Tamim, 2013), which begs the question: *What more can be done?*

It is challenging for researchers and healthcare professionals to understand why a pregnant woman would choose to drink when the message is clear—there is no known safe amount of alcohol use during pregnancy and no safe time to drink. When a mother drinks, so does her baby (American Pregnancy Association [APA], 2014; CDC, 2014a). However, even the most obvious message can become obscured. For every word of warning, there are two refutations. Amid an alcogenic society "steeped in denial and marinated in a high tolerance for alcohol-related harm" (Johnston, 2013; Ryan, 2011, para. 4), it is not uncommon for women to receive mixed messages about the effects of alcohol on a developing fetus from research, the media, peers, and even their own physicians (Wozniak, 2014; SAMHSA, 2015). This conflicting information complicates a woman's choice to abstain, her sense of health and well-being during pregnancy, and the strategies employed to help her make informed decisions (Meurk, Broom, Adams, Hall, & Lucke, 2014). Advocates worry about the inconsistencies of the views expressed and believe that it is necessary to speak with one voice. Without uniformity, there is a risk that women will look for or hear only what suits them.

Meurk and colleagues (2014) highlight the competing cultural norms that simultaneously encourage and discourage alcohol consumption, putting pregnant women in a precarious spot. On the one hand, drinking is celebrated as an enjoyable, communal pastime. Alcohol use is often an integral part of business networking, socializing, and relationships (British Columbia Centre of Excellence for Women's Health [BCCEWH], 2013). It may be challenging for women to abstain in these situations where drinking is expected and non-participation is frowned upon. On the other hand, drinking is discouraged through the disapproval of drinking during pregnancy and wellness guidelines that advise abstinence to support healthy fetal development (APA, 2014; CDC, 2014a). Here, a woman's motivations to abstain may be divided—to promote optimal fetal health or to avoid feelings of judgment, guilt or shame. Risk appears to be an important consideration for pregnant women; however, this concern is clouded by disputed evidence, conflicting opinions, and discussions of personal and social identity (Meurk et al., 2014).

Researchers put forth 6 reasons to explain maternal alcohol consumption during pregnancy, which coincide well with the 3 areas of research presented in this dissertation. The first two reasons center on awareness—a key component in ***prevention*** efforts*:* 1) women are unaware they are pregnant and 2) women lack awareness about the damaging effects of alcohol on a developing fetus. The third reason highlights the need for early ***assessment*** and diagnosis, targeting developmental delays and functional deficits where physical abnormalities do not exist: 3) women underestimate harm due to the healthy appearance of children from peers who consumed alcohol during pregnancy. The final 3 reasons detail contextual factors (e.g., social circle, environment, family history) surrounding alcohol use that should be focal points of ***intervention*** and support services for affected individuals, families, and communities: 4) social drinking is the norm in a woman's friend group; 5) alcohol may be used as a means of coping with domestic/family violence, poverty, isolation, or mental illness; and 6) women struggle with alcohol addiction (BCCEWH, 2013; Environics Research Group, 2006; Jones & Telenta, 2012; Meurk et al., 2014; Skagerstróm, Chang, & Nilsen, 2011; Walker et al., 2013).

In an era of personal choice and freedom, it is not surprising that women would choose to follow counsel that fits their lifestyle, making changes that appear more manageable or positive to them (DualDiagnosis.org, 2015). In other cases, women may continue alcohol use because of an addictive attachment, familial alcoholism, or difficult life situation (e.g., poverty, violence, depression) (BCCEWH, 2013; DualDiagnosis.org, 2015).

Prevention

"The first step toward change is awareness. The second step is acceptance." Nathanial Branden

The driving force behind awareness and prevention strategies in FASD is to ***eliminate*** the condition (Gass, 2014). Through routine screening for alcohol use among pregnant women and women of child-bearing age, improved education of healthcare professionals, compassionate care of at-risk women, and increased visibility of harm and injury, the goal is to convey a clear and incontrovertible message that drinking alcohol during pregnancy is dangerous and damaging (Warren, Hewitt, & Thomas, 2011). The hope is that if prevention efforts fail to eliminate FASD, improved and targeted strategies can reduce incidence of the condition and enhance the quality of life of affected individuals (Warren et al., 2011).

FASD affects all segments of society; thus, prevention efforts must be far-reaching, consistent, and sustained (Gass, 2014). Few organizations understand this challenge better than the Alberta PCAP Council—a group dedicated to preventing alcohol- and drug-exposed births and helping mothers build healthy families and stable homes (Government of Alberta, 2013). Developed by Dr. Therese Grant at the University of Washington, PCAP emphasizes a multidisciplinary, comprehensive, and coordinated approach to intervention founded on the principles of connectedness, acceptance, personal efficacy and change, harm reduction, and support (Parent-Child Assistance Program [PCAP], 2010). In order to be effective, programs for high-risk mothers must take into account the intricate nature of women's issues (PCAP, 2010) and provide services that target the *people* (mother and child) rather than the *problem*. This aim befits the research completed with prevention specialists wherein the objective was to ascertain understanding of the participant's personal experience and how this influences his/her work, especially in terms of drive, purpose, healing, empowerment, and connection to the cause and families served.

Manuscripts 1 and 2 report the personal and professional experiences of FASD prevention specialists working with affected and at-risk women and children through a novel, multi-methods approach. Focus group discussions explored frontline workers' thoughts on programming and service delivery—wherein lie the strengths, challenges, and areas for improvement—as well as how collaborations, research, and accepted practice inform strategic planning for prevention and intervention activities. Visual methods (quilting and photographs for video) engaged participants' psyche and creativity, providing an avenue for emotional expression so often suppressed. A primary goal of using two different qualitative methodologies was to enhance participant and researcher connection to the inquiry. The formation of stronger research links between participants and researchers alike is seen as an important goal in the development of evidence-based practice aimed at providing positive outcomes for service providers and recipients. If the aim is to create programs and services that effectively reflect the needs, values, and interests of the children and families served then it makes sense to engage stakeholders as much as possible in research that emphasizes shared experience, collaborative planning, and cooperative service delivery.

Assessment

"Assessment is a verb, a process, and a relationship." Angela Valenzuela

Expanding the scope of assessment and diagnosis to encompass the *whole child* emerges as a necessary and important initiative in the move toward improved recognition of alcohol as a toxin that can affect the developing child years after he/she is born physically healthy. The initial appearance of health and well-being of a baby is a major reason pregnant women continue to drink alcohol (BCCEWH, 2013; Skagerstróm et al., 2011). Many women are aware of the possible harm alcohol and drugs pose to a developing fetus; however, they underestimate the damage alcohol consumption can cause because they know other women who drank during pregnancy and their children seem healthy (BCCEWH, 2013). However, what is commonly misunderstood is the timeline for deficit detection. The effects of PAE can be diverse, discrete, and often unseen until years later in development when higher order cognitive processes and behaviors begin to emerge (Rasmussen & Bisanz, 2009). It is for these reasons that a *gestalt* approach to assessment and diagnosis is recommended, appreciating that the end result is well more than the sum of its parts.

Indeed, the evaluation of a child with an FASD is always best interpreted and understood in light of the child's complete story including his/her family background, personal attributes, learning and behavioral profile, school performance, cultural factors, and educational needs (PACER Center, 2015). To truly see the whole child, these *details* must be woven together in a precise manner—conveying the *big picture* or purpose of the assessment, which are the goals for intervention and action. This can only be achieved through conversation and collaboration with key stakeholders such as the caregivers, teachers, administrators, counselors, and caseworkers. Each stakeholder provides a different perspective and 'puzzle piece,' which is critical to the arrangement but makes limited sense without prior understanding of the big picture of which it is a part (van der Westhuizen, n.d.).

Manuscript 3 takes the message of awareness and prevention to the schools where experts across North America estimate that the full range of FASDs is between 1-5% of school-age children (Health Canada, 2006; May et al., 2014; May et al., 2009). These estimates increase the likelihood that a teacher will encounter one or more affected children during the course of his/her career; thus, reinforcing the importance of assessing the educational impact of FASD from multiple perspectives and the preparedness of school personnel to meet the needs of this specialized student population (Pei et al., 2013; Poth et al., 2014). The school is unlike any other setting in which the child with FASD will operate. Unique opportunities arise in the school to observe the individual set of challenges experienced by affected students, allowing for greater discernment of developmental differences when compared to typically developing peers (Kalberg & Buckley, 2007). Kalberg and Buckley (2007) suggest that, "it is helpful to think of the environment as an external nervous system of the child, a place where external (environmental) supports can be implemented to bolster the deficit areas of the child" (p. 282). This is an inspired premise that first requires comprehensive knowledge of the areas of disability (assessment) and a specific plan to mitigate secondary disabilities and capitalize on strengths and abilities (intervention) (Paley & O'Connor, 2009; Popova et al., 2012; Streissguth et al., 1996; Streissguth et al., 2004). In the present study, participants highlighted the necessity of receiving information about the affected child's cognitive and academic strengths to build effective interventions but agreed that this information means little to the development of successful programming and skills in the absence of a complete learning and behavioral profile and understanding of social and emotional needs (Hannigan & Berman, 2000; Green, 2007; Paley & O'Connor, 2007, 2009).

The most significant contribution of the assessment piece to this dissertation is the challenge to reconceptualize assessment and how it is used in the schools for students with FASDs. An overarching framework for psychological assessment has been *reactive*—responding to identified problems through evaluation to give "cause" for learning, behavior, and emotional problems—rather than *proactive*—emphasizing strengths and abilities in coping and educational resilience (Dugle & Grigorenko, 2015; Herz, 2013; Klin et al., 2005). Described another way, assessments often focus on what the child *cannot do*— or what they struggle to do—rather than suggesting areas in which they demonstrate strengths (Mastoras et al., 2011). Instead, assessment should be viewed as a process of initiating intervention. In this way, stakeholders move away from ‘diagnosis for disability’ and instead move toward “assessment for intervention.” This encourages stakeholders to approach assessment in a proactive way, doing away with the “wait to fail” model in favor of a “work for success” one.

Included in this new assessment philosophy is an inclusive and multi-layered approach to psychological testing within a collaborative context. This means working as a team with the affected child’s parents, teachers, school administrator, and other allied professionals in order to gather information and come up with a strategy for the assessment that is tailored to each child and family’s unique situation, concerns, and needs (Exceptional Learners Associates, 2015). If the purpose of an assessment is to draw the evaluator and reader closer to improved understanding geared at creating success for the whole child then it is paramount that the assessment connects in language, specificity, and usefulness (Pei et al. 2013). Strong associations between stakeholders are key. This means that each person sees their perspective utilized, and that the information shared is valuable and practical for each person’s dealings with that child. Such an approach will help with the development and acknowledgment of the “details” (e.g., building coping skills and emotional control, improvement of cognitive and learning strategies, and reinforcement of positive behaviors) as well as involve families in the process of advocating for needed and warranted services for their children and themselves (Pei et al., 2013). Assessments geared toward intervention can provide the catalyst and guidance for this type of communication and collaboration and help schools fulfill their primary goals, which are successful outcomes for the whole child with an FASD and ALL children regardless of ability or disability (Kochhar-Bryant, 2010).

Intervention

"It is not enough to make the case in facts and figures. People have to believe in the change, own it, and live it." Chris Jones

A central feature of successful school and community programs is a focus on the *individual*, using interventions to address difficulties, monitor change, and track progress. Regardless if the intervention is designed to meet the needs of a whole class, a small group of students or one child, the best strategies still keep the individual student in mind (Alber, 2011). Prevention and assessment often approach FASD from a broad platform, employing a 'divide and conquer' strategy to attend to multiple issues at once. In prevention, efforts are concentrated on awareness campaigns, screening, prenatal and postnatal support, counseling and education, and research to affect change at a global level (Poole, 2008). In assessment, information from various sources and assessment tools allow the evaluation team a comprehensive look at abilities and functioning to determine appropriate diagnosis, placement, and services (Glenchur, 2012). Intervention can be universal be it can also be selective—addressing the needs of a small group of children or an individual child. More targeted interventions work at ameliorating specific skills or behaviors that challenge children with FASDs that do not pose difficulty for a wider group of their peers. It's about filtering through all of the information gathered and finding what is most important to pursue, unlocking opportunities for greater engagement, growth, and achievement (Jones, 2013).

Accompanying manuscripts 4 and 5 in their shift from assessment to intervention is a comprehensive look at the educational impact of FASD from multiple perspectives. It is well known that the path to improved student outcomes is paved with teacher knowledge, preparation, and collaboration. This is no truer than in the field of FASD. The complexity and sensitivity of the condition require that teachers are well trained, mentored, supported, and included in student plans and educational decisions (Alber, 2011; Blackburn et al., 2010; Green, 2007; McCarty et al., 1999; Streissguth, 1997). In the intervention studies, findings revealed a continued lack of awareness and knowledge of FASD among educational professionals. Fundamental understanding of FASD and evidence-based practices are critical to the design and implementation of superior educational practices and support services. Certainly, the effectiveness of services is greatly dependent upon the quality of the intervention that is delivered and received by affected children and families and the knowledge and skill of service providers (Moore, Ochiltree, & Cann, 2002). The greater the discretion and time given to capacity-building of school personnel and professional support staff, the more weight is assigned to the message that excellence in training, monitoring, and service delivery is hugely important to the provision of high quality, responsive educational and support services for children with FASD and their families (Moore et al., 2002). To heighten this message, it is also imperative that teachers and allied professionals feel a part of the intervention process from day one, being fully included in educational decision-making. This will help for them to see their role as collaborative rather than directed, and increase their commitment to implementation and professional development (Alber, 2011).

Collaboration was indeed a major theme that emerged across all roles as paramount to the success of appropriate educative environments for children with FASDs. Participants highlighted mutual respect and honest, open communication as key to fostering positive, collaborative relationships between administrators, classroom teachers, allied professionals, and caregivers (Job et al., 2013). Working in collaboration and consultation can also help to break down walls of distrust and ignorance, allowing caregivers to share contextual information to consider in educational planning and school personnel to develop beliefs and practices based on accurate and complete information. Once the beliefs and practices of administrators, teachers, and allied professionals have been reframed, they are in a better position to evaluate resources and programs and initiate interventions with the affected child in mind. It is equally important to include the family in intervention planning (Olson, Oti, Gelo, & Beck, 2009). Research from this dissertation and previous studies report on the inimical or aloof experiences families of children with FASD have encountered with school personnel, resulting in reluctance to partner with educators and trust their educational decision-making. Therefore, it is especially critical for administrators and teachers to invite caregivers into conversation and involve them directly in intervention planning and monitoring to rebuild relationships and create accord between home and school (Olson et al., 2009). The present research underscores the importance of recognizing value in collaborative planning and intervention, which serves to increase accountability and collegiality as team members work together toward successful outcomes for children with FASDs (Green, 2007; Job et al., 2013; Timler & Olswang, 2001).

"In a world where everyone pushes *content*, it's time to focus on *context*" (Jones, 2013, para. 5). Three main reasons for increased risk of alcohol use during pregnancy emphasize the challenge of pushing against environmental (e.g., social drinking, poverty), maternal (e.g., addiction, depression), and family (e.g., family violence) factors that for years have been the norm (BCCEWH, 2013; Environics Research Group, 2006; Jones & Telenta, 2012; Meurk et al., 2014; Skagerstróm, Chang, & Nilsen, 2011; Walker et al., 2013). Researchers have highlighted a host of other context concerns to be considered when gathering information to support affected children and intervene in areas of struggle and delay through a comprehensive, ecological approach (see Figure 1) (Abel, 1998; Bingol et al. 1987; Center for Early Childhood Mental Health Consultation [CECMHC, n.d.); Coggins, Timler, & Olswang, 2007; May et al., 2005; May et al., 2009; Rubio, Kraemer, Farrell, & Day, 2008; Streissguth et al., 2004; see May & Gossage, 2011 for a comprehensive review).

Research suggests that some of the most effective interventions focus their efforts on the family as much as the affected child. For many caregivers, the cognitive, emotional, and behavioral difficulties experienced by their children are more than they can manage (Kalberg & Buckley, 2007; Ryan & Dybdahl, 2009). Since the family environment impacts a child's development, it makes sense to operate from a *whole family* perspective. Support by way of social services, education, training and respite is therefore advantageous, helping caregivers to maximize their adjustment and functioning for the health of the family (Kalberg & Buckley, 2007). It is understood that strong families and communities are vital to the health and wellbeing of affected children (Moore, Ochiltree, & Cann, 2002). "Successful interventions cannot be imposed from without" (Moore et al., 2002, p. 14); they must come from *within*—their schools, their communities, their families. When interventions consider children in the context of their families and communities and respond to the needs identified by administrators, teachers, caregivers, and allied professionals (Moore et al., 2002)—people who know and support them—the likelihood of success is immeasurable.

The Whole Package

Much like creating a care package for a loved one far away, the process for developing an effective intervention takes considerable thought, time, and precision. With a care package, a great deal of forethought often goes into the planning and preparing to ensure successful delivery

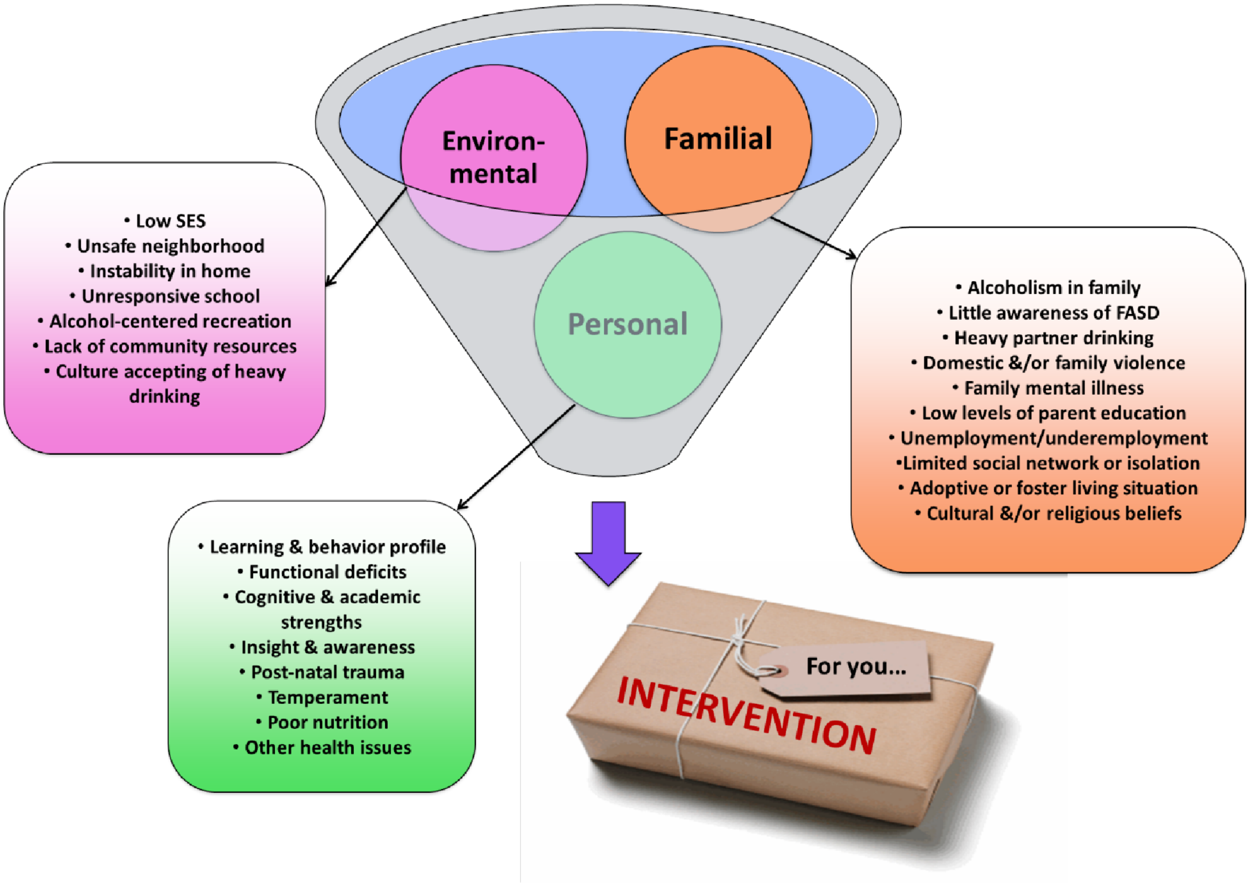

Figure 1. **Contextual factors to consider in the design of FASD-specific interventions**

and utility of the contents. It is also not uncommon to enlist the help of others who know the receiver well for input, ideas, and items. Sometimes, the sender will choose a theme and include things particular to it. Other times, the items selected will span a few areas. The idea is to have the receiver open the box to find a special gift tailored to his/her unique qualities, values, interests, and needs. It is helpful to think of the development of an individualized intervention for a child with an FASD in like ways. Careful consideration of the whole child in context guides collaborative planning, design, and implementation of the intervention targeting one or more problem behaviors or skill deficits. Caregivers and classroom teachers serve to provide personal information about the child including rewards that motivate and strategies that engage. For example, Andrea, a focus group teacher, employs “thumbs up, thumbs down” for visual learners in her FASD-centered classroom. A “thumbs up” signals on-task behavior so the affected child can keep on working without too much pause and a “thumbs down” alerts the child that he/she is displaying a behavior that needs to change (Job et al., 2013). Administrators can speak to the logistics and feasibility of carrying out the intervention, organizing staff training and setting expectations for evaluation and documentation. Lastly, allied professionals provide specialized knowledge related to reasonable and measurable goals and objectives, data tracking and progress monitoring, predictable gains, and evidence-based practice. The aim of the intervention mirrors that of the care package. To filter down assessment data, academic evaluations, family and developmental history, and anecdotal information into a customized intervention specific to the learning and behavioral needs of the affected child, incorporating strategies that will best address his/her particular difficulties and highlight his/her strengths to bring about growth and gain.

Summary

The research presented in prevention, assessment, and intervention is bound together by a person-first, FASD-informed approach to inquiry and dissemination. Likened to the ‘whole child’ initiative, an FASD-informed approach considers the child with an FASD across settings, understanding that he/she may be affected in a variety of ways (e.g., cognitively, socially, emotionally, or spiritually). Therefore, to benefit from programs and services, adaptations must be made to meet the unique needs of the affected child (Nota Bene Consulting Group [NBCG] & BCCEWH, 2013b). An FASD-informed approach recognizes that change needs to occur at the program level rather than expecting the child with an FASD to fit to current practices (Gelb & Rutman, 2011; Malbin, 2002). This calls for knowledgeable service providers to continue to work within existing service delivery systems to make them more FASD-informed. Multiple service providers may work with this population but not all work *well* with this population

(Casto, 2013). Stakeholders in the present studies highlight challenges to prevention, assessment, and intervention work with affected children and families and suggest changes to current systems for improved collaboration and care.

Prevention efforts bring about a greater awareness of FASD through campaign, conference, community service, and discussion. The goal is to decrease judgment and increase acceptance, making it safe for at-risk or affected women, children, and families to access information and services (Job et al., 2013). Where prevention helps to confirm need, assessment serves to reveal damage and disability and suggest areas for intervention. Intervention works to improve skill, function, and coping so that affected individuals can lead healthy and fulfilling lives (Duquette et al., 2007; Green, 2007; Ryan & Ferguson, 2006a, 2006). It is a data-informed process wherein each step informs the next and decisions follow a common path towards positive, lasting change—from awareness to understanding to treatment to elimination. Research presented in this dissertation contributes significant experience-based knowledge about best practice in prevention, assessment, and intervention but we remain diligent in our fight for abolition.

CHAPTER V

IMPLICATIONS

> Knowledge is a gift best appreciated when we don't try to think about it…it grows more elusive as we attempt to draw closer to its source. And though we make complex decisions every day, we routinely fail to grasp what it means to *truly understand* something. For many reasons, we fail to engage what's presented in a discerning way…*it's high time we raised the bar on how well and how deeply we dare to think*. (Jones, 2011, para. 1-3)

This dissertation seeks to challenge current perceptions and conceptions about FASD. FASD is not about a condition or a field of study or a cause. It's about *people*—the families we serve, the children we teach, and the effect those interactions have on our lives. It is for this reason that the studies included in this dissertation follow a person-first approach, recognizing that change begins with honest conversation that focuses on emotion as much as intellect. It is difficult to research FASD without coming across the word *passion* (e.g., Fuchs, Burnside, Marchenski, & Mudry, 2009; Milne, 2014; Pelech et al., 2013). Passion is described as an "intense, driving, or overmastering feeling or conviction" (Merriam Webster Dictionary, 2015). A compelling dedication to someone or something necessitates talk about the emotions fueling the cause. Engaging the lived experience is how we achieve a deeper level of understanding and belief in the value of our work. To see the imperceptible, hear the unacknowledged, and reveal the suppressed story, and engage *all* that is presented—that is the true measure of discernment.

The present dissertation contributes to the academic literature on FASD significant knowledge gained through study, conversation, and collaboration and successfully meets the research objectives delineated. The introductory chapter provides an overview of FASD and its related health, social, and educational challenges. Additionally, associated difficulties were at the center of focus group conversations across all projects. Administrators, teachers, caregivers, allied professionals and prevention specialists detailed their personal experiences with the myriad of deficits (e.g., physical, learning, behavioral, emotional, and social) overwhelming affected children and described their approaches to management, care, and support. Successful and failed strategies alike became a part of a collective experience anchored in relationship, inclusion, empathy, and community. It was a pleasure for researchers to witness the participants share their stories—affirming one another's struggles, validating feelings of weariness and frustration, and imparting better ways of working with affected children and families.

Working with children with FASDs and their families can be a taxing and isolating job; such is the need for conversation and collaboration among invested individuals to allow them to see that they are very much a part of an important community and that their work contributes greatly to our understanding of what constitutes best practice in FASD prevention, assessment, and intervention. In tandem with a comprehensive examination of current practice in the field, this component fulfills and supplements the second research objective, which was to review relevant research with the goal of generating shared understandings related to optimal service delivery and systems of support.

The third objective asserts the researcher's intention to document stakeholder experiences with planning and delivery of FASD programs and services using a qualitative, multi-methods approach. This aim was achieved through multiple focus groups, interviews, and visual methods. A total of 11 focus groups and 3 interviews were conducted, lasting on average 1 hour. Of the focus group sessions, 7 were completed with prevention specialists, 1 with administrators, 4 with classroom teachers, 1 with caregivers, 2 with allied professionals, and 3 with a mix of school, community, and caregiver roles. Interviews were obtained with 2 caregivers and 1 administrator. Each session was guided by 8 semi-structured interview questions (see Appendices C and H). Keeping in mind the research objectives, questions were prefaced by a short opening. For example, the introductory paragraph for prevention specialists was as follows: “We want to learn from you and from your experiences of collaboration and use of research in FASD-related planning and/or delivering of programs and services. So, please think back to the experiences of being involved in these processes.” The goal of documenting participant experiences was central to the conversation; and so, each part of the focus group or interview (i.e., introduction, key questions, and summary points) emphasized stakeholder expectations, ideas, and experiences. With respect to the planning and delivery of FASD programs and services, focus group and interview questions were designed to target key areas of involvement.

To gather information about assessment and intervention, administrators, teachers, caregivers, and allied professionals were asked questions directed at knowledge and beliefs and their experiences with the assessment process, diagnosis, challenging behaviors, and strategy implementation. Prevention specialists were asked about PCAP program changes, strengths and challenges in programming and service delivery, training, and the use of research and best practice in strategic planning. These questions enabled researchers to gain a wealth of information about main areas of interest and meet established research goals and objectives. Although the quilting activity was used solely with prevention specialists, its success in engaging PCAP members and providing rich emotional detail suggests that it could be a valuable and gainful method of data collection with stakeholders across settings as well as other special populations, especially in research about sensitive, intricate, and abstruse topics.

A fourth objective centers on the contribution of the present research to the existing academic literature on FASD. The intent was to highlight features of a planning and service delivery approach and evidence-based practice that have the potential to be replicated and lead to positive outcomes for stakeholders and affected children and families. The result is one better—a model of collaborative planning and integrated service delivery which serves to describe the processes necessary for authentic conversation and collaboration that affects change for invested stakeholders and children with FASDs (see Figure 2). A theoretical framework based on the theories of phenomenology and ecological systems and principles of a holistic, FASD-informed approach to education and care guided qualitative inquiry of stakeholders' experiences in FASD prevention, assessment, and intervention. The focus of phenomenological study is the 'lived experience'—to understand *what* a person experiences and *how* he/she experiences it (Patton, 1990), and through multiple participants reveal the essence of a 'shared experience' underlying the individual stories (Rossman & Rallis, 1998). This theory befits the study objectives precisely as the personal and professional experiences of participants were of primary importance.

Researchers sought to document the experiences of participants across school and community settings as they work to care for, support, and educate FASD-affected children and families. Individual experiences were reviewed and compared to find commonalities that became a part of a collective description of current practice in the field and shared position on where to focus efforts for more collaborative planning and service delivery. Our emphasis on the stakeholder experience in multiple systems (e.g., community prevention efforts or school-based assessments) expresses an ecological consciousness—acknowledging that everything in the world exists in context, and that the child with an FASD operates within several systems of influence (Poth et al., 2014). A holistic, FASD-informed approach to care and education necessitates an understanding of the environmental factors that influence the affected child's

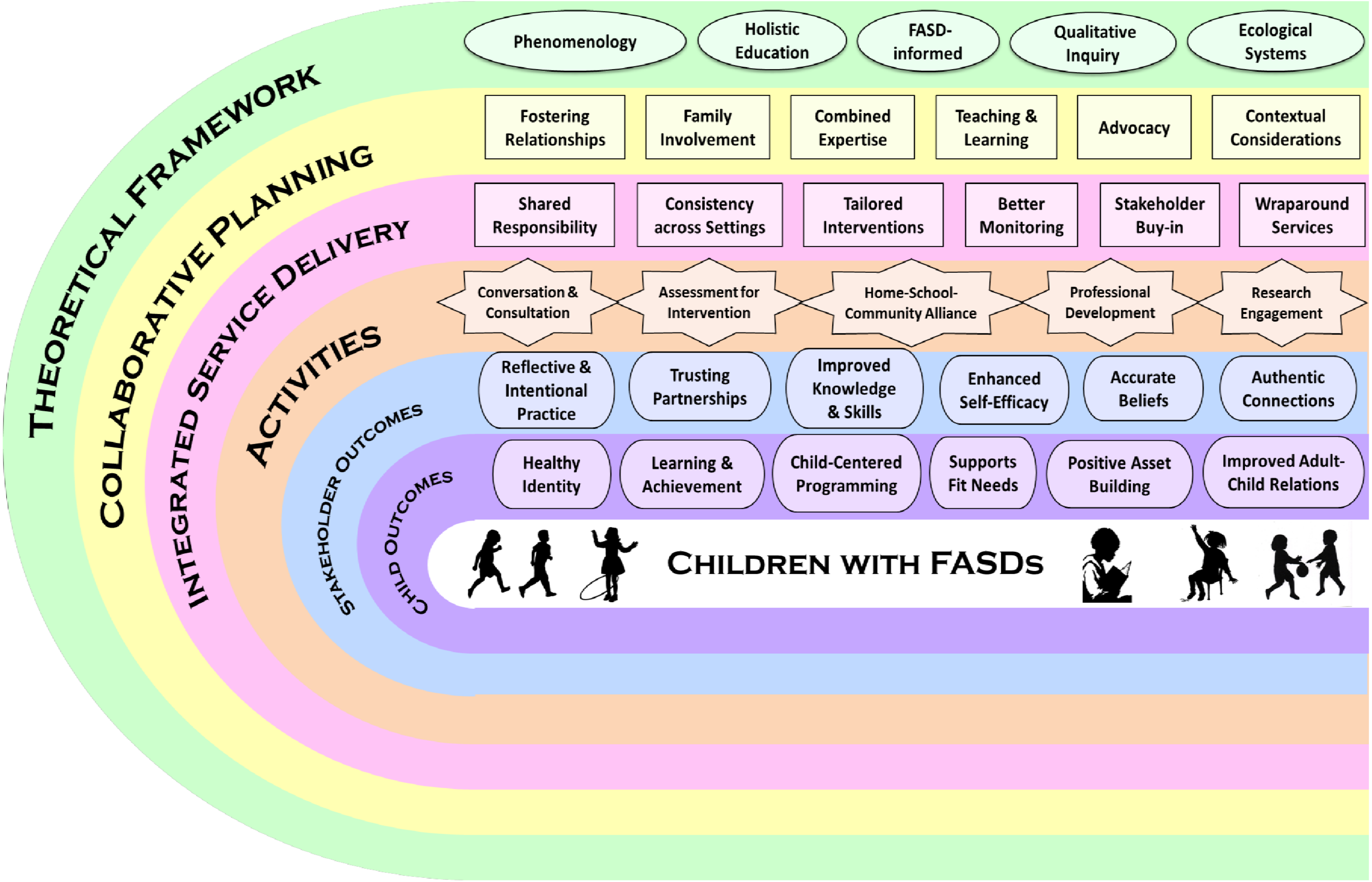

Figure 2. **Model of collaborative planning and integrated service delivery for improved stakeholder and child outcomes**

learning and development and foster the diversity of children we encounter. Ecological systems theory emphasizes the varied, interrelated environmental systems in which children grow (Bronfenbrenner, 1979). It is critical for stakeholders to be mindful of these networks of influence when designing interventions and delivering services, as a coordinated, collaborative course of action is the best way to bring about lasting holistic and systemic change (Rogers-Adkinson & Stuart, 2007).

The decision to use a qualitative, multi-method approach in our study with prevention specialists, joining the novelty of a quilting activity with the familiarity of focus group discussion, allowed for reciprocity in teaching and learning between researchers and participants and gave rise to enhanced ecological understanding (Job et al., 2012) adding context to response. Participants across studies lauded the researchers' qualitative approach, highlighting its storied emphasis as a positive feature where previous survey involvement felt inadequate and futile in their effort to record stakeholders' experiences and offer suggestions for practice. Their commentary pointed at many of the pitfalls met by communities in research including poor methodology, failure to communicate findings to the participants, communities feel over-researched and underappreciated, and research is of little benefit the community (Hartwig, Calleson, & Williams, 2006). Unfortunately, it is not uncommon for research designs to inappropriately involve community participants, resulting in a negative perception of research and wariness to respond openly and honestly (Hartwig et al., 2006). Investigators in the present studies were mindful of these issues and worked hard to increase the value of participation so that stakeholders felt like partners rather than subjects.

School personnel, caregivers and allied professionals were given the option of attending a focus group at the university or on site at their school or community agency. Flexibility in process was also available. Stakeholders participated in interview, role-specific focus groups or multi-role focus groups. This proved an excellent way to make participants feel comfortable and respected, and added greatly to their perception of others' function in school and community activities. Researchers were hesitant to combine roles within groups for fear of silencing some whose administrator was present. However, this did not appear to be an issue. Instead, the multi-role groups provided some of the richest commentary, underscoring the advantages of collaborative work yet remaining honest about the struggle to involve families, foster positive working relationships, and advocate effectively for affected children. The dynamic between stakeholders was absorbing as participants showed genuine interest in the lessons of others. There was validation of strife and brainstorming of ways to create more FASD-informed systems of support. The merging of knowledge and expertise as participants expanded on each other's responses highlighted the usefulness in bringing different parties to the planning table. When the cause is great, we sometimes fear that letting others in will take away from our mission but in reality, it is just the opposite. The addition of skilled and knowledgeable players strengthens our team and increases the likelihood of long-term success.

Collaborative planning is about individuals committed to working together towards a common goal. It is about putting aside the personal agenda for the collective one, and elevating system change as a fundamental path to successful outcomes for children with FASDs. Finally, the delivery of participant summaries to each focus group and interviewee provided evidence that researchers heard their stories and valued their contribution. It also enabled investigators to think about research in new ways—as a partnership wherein both researcher and participant have equal stake in the project and can achieve like reward. When one approaches research with the mindset that he/she will be a recipient of knowledge as much as a communicator, the personal and professional growth is assured.

Altogether, the findings across manuscripts support an integrated model of service delivery that incorporates 6 main ideas: *responsibility, consistency, individualization, monitoring, stakeholder buy-in,* and *wraparound services*. A key area of conversation in support of collaborative planning was a push for shared responsibility in the design, implementation, and evaluation of interventions and support services. It was suggested that an expectation of collective ownership be put forth in the planning phase of interventions to strengthen stakeholder's commitment to successful outcomes. When a framework of community (i.e., caregivers, community partners, school personnel, and allied professionals) ownership is established, stakeholder buy-in deepens and support of joint efforts increases. This serves to enhance the probability that each person will do their part to assist the affected child and/or family in meeting goals for learning and skill development and monitor and track intervention effectiveness (Alberta Education, 2009). Shared responsibility also implies increased accountability wherein the expectation is that stakeholders will do their best to apply strategies consistently and that every effort will be made to support teaching and learning across settings. Participants agreed that frequent and frank communication between home and school is an essential component of successful child outcomes and key to structuring a mutually supportive environment (Job et al., 2013).

The final two suggestions for integrated service delivery concentrate on the needs of the individual child with FASD and how he/she can best be taught, encouraged, and nurtured. An FASD-informed approach lends itself well to the principles of holistic education wherein programming and supports take the whole child into account by matching services well to the child's educational and behavioral needs, learning style, developmental level, abilities, and interests (Alberta Education, 2009). The advantage to establishing a standard of collaborative planning is that stakeholders outside the family become better informed about the affected child and thus, are in a stronger position to tailor interventions according to his/her unique learning profile. This increase in knowledge and capacity also benefits caregivers. When caregivers believe something needs to change for their child, they can feel comfortable to approach school personnel and allied professionals to discuss their observations and concerns as team members in service delivery (Alberta Education, 2009; Job et al., 2013; NOFAS-SD, 2009).

Improving the lives of children with FASDs and supporting affected and at-risk families in healthy child development requires a cooperative community effort. Successful collaboration involves teachers, caregivers, students, and administrators but also community service providers in prevention, healthcare, mental health and developmental disabilities, and social services. Stakeholders in this collaboration should be flexible and accommodating and draw on all expertise available in the affected child's school and surrounding community (NOFAS-SD, 2009). Wraparound services take an involved, holistic approach to child and family wellness and are in line with the proposed model of collaborative planning and integrated service delivery. The theory behind wraparound is 'systems of care,' which emphasizes a coordinated network of mental health and related services organized to support the multifarious and changing needs of children and families (Pires, 2002). This orientation engages the individual *and* the collective to meet the unique challenges of the child with an FASD as well as school and community stakeholders in their collaboration towards systemic change. The process is meant to teach families how to access 'natural support' through the strengthening of interpersonal relationships and utilization of resources within already existing social and community networks (National Wraparound Initiative [NWI], 2014). Wraparound services revolve around a partnership between community agencies, schools, and families to help overcome barriers to learning and healthfulness. Consultation, support, and capacity building for invested stakeholders are equally important components of the wraparound philosophy (Scott & Eber, 2003), making it more holistic than traditional care and resulting in interventions that are effective and impactful. Wraparound plans and services follow a principle of '*voice and choice*,' which holds the viewpoint of the family in the highest regard (NWI, 2014). This principle optimally describes the perspectives of stakeholders in the present studies with one important modification—the voices and choices of **ALL** team members are of equal value in an approach to planning and service delivery that is truly collaborative and integrative.

In order to be effectual in collaborative planning and integrated service delivery, stakeholders put forth several requisite activities that relate to specific stakeholder and child outcomes:

1. Conversation and consultation

Transparency in process and practice is paramount to building trusting relationships and engaging stakeholders in collaborative activity toward improved outcomes for children with FASDs. Foundational to transparency is open and honest conversation and consultation with invested parties wherein the contribution of the individual is recognized and respected as critical to the collective goal. Important to the cooperative effort is establishing common ground in terms of objectives, expectations, roles, and definitions of success. Stakeholders agreed that early and frequent conversation between home and school contributes greatly to the effectiveness of interventions and overall student achievement (Job et al., 2013).

Authentic connections. Across focus groups, interviews, and quilting pieces, the connection between affected children and advocates was highlighted as critical to the success of prevention and intervention services. Among the major strengths of FASD-related programming, especially in community support, is the association of relationships to successful outcomes. Creating authentic connections by way of getting to know children and families, reflective supervision, supporting colleagues, and collaborating with allied service providers appears equal in worth to any prevention, assessment or intervention activity. In the quilting illustrations, connectedness was suggested through images of holding hands, pathways, circles, and people (Atkinson et al., 2013; Job et al., 2014). In conversation, stakeholders emphasized the importance of interaction to self-knowledge, purporting that we learn best about our subject matter and ourselves in relationship and communication with others (Job et al., 2012; Job et al., 2013; Poth et al., 2014).

Reflective and intentional practice. Findings across studies support a framework to planning and service delivery that is intentional and reflective. In our study of prevention specialists, an important lesson was learned about community-based research. Remaining reflective and engaged is vital to the learning process and enhances researcher's credibility with community members. There is an authenticity that comes with being present in research activity, making a concerted effort to connect with and learn from participants. This approach bridges the gap between researcher and "researched" and allows for information to come from a more personal and intentional place. Intentionality in practice necessitates a similar sincerity, taking steps to understand the complex needs of children with FASDs and being selective in the environment, strategies, and services chosen to support learning and achievement (Poth et al., 2014). Reflection follows intentional practice through the evaluation of decisions, actions, and outcomes to shape future action, creating a system of practice that is thoughtful, flexible, and responsive.

2. *Assessment for intervention*

In the move towards a more collaborative and integrated model of planning and service delivery, stakeholders call for a fundamental shift in our thinking about assessment. It is submitted that assessment be re-conceptualized from an exercise of determining disability to a process of initiating intervention, considering the whole child within his/her environment in order to best match needs to supports and resources (Pei et al., 2013). This provides the opportunity to approach assessment in a proactive way; thus, avoiding the "wait-to-fail" model and moving toward a "work-for-success" model. This perspective holds need above diagnosis, suggesting that intervention should not be contingent on receipt of a label but based on assessment data that shows delay and difficulty requiring remediation. Due to the complex nature of FASD, many children fail to receive a diagnosis despite showing great need for specialized services and supports (Harding, 2015). Attributing intervention to diagnosis has significant implications for intervention and therapeutic services, and can impede affected students from receiving the assistance they so desperately require. By moving to an assessment for intervention framework, a fluid process of informed responding is created that recognizes people over procedure (Pei et al., 2013).

Child-centered programming. Individualized intervention is about child-centered programming—making curricular and service adaptations in response to deficit and ability and advocating for support and resources that take into account the whole child. Researchers have been divided in their views of how educators and service providers should approach intervention with this special population. Some concentrate on learning and achievement, gearing intervention ideas toward behavioral reframing and educational goals (Green, 2007; Dybdahl & Ryan, 2009; Jirikowic et al., 2010; Olson et al., 2005) while others focus on the emotional and psychological health of students, creating programs that promote the development of self-worth, emotional regulation, and personal identity (Benz, Lindstrom, & Yovanoff, 2000; Lindstrom et al., 2007). An emerging trend in conversations with stakeholders in the present study and other investigations involved in the education and care of students with FASD is the support of character development in addition to skill development (Rogers-Adkinson & Stuart, 2007). Academic learning and achievement is no longer the sole objective of educators and allied professionals as stakeholders are recognizing the need for time to be devoted to the building of confidence and identity to ensure successful outcomes that extend beyond the classroom (Poth et al., 2014; Rogers-Adkinson & Stuart, 2007). This perspective is in line with a holistic, child-centered approach to programs and services set forth in the present research wherein the unique needs of the child are considered and developmentally appropriate practice guides skill development across social, emotional, physical, and cognitive domains (Kochhar-Bryant, 2010; Poth et al., 2014).

Supports fit needs. The ability to successfully match learning supports with need is based on the shared view of the importance of individualized programming for children and families affected by FASD. Participants across roles stated that it is not enough to have professionals and families just talk about needs and strategies but that children with FASDs require active collaboration to plan, implement, and evaluate supportive interventions that will advance knowledge and skill (Pei et al., 2013). Although the push for increased communication between home, school, and community is great, stakeholders agreed that conversation without action is of limited value in creating positive change.

The successful match of support to need was highly evident in discussion about assessment. Stakeholders noted a disconnect in use of assessment data to inform intervention decisions. Currently, assessment seems to be focused on the *product* (e.g., assigning a diagnosis or establishing special education eligibility) rather than the *process* of determining need and designing programs that capitalize on strengths and address skill deficits. For complex populations such as children with FASDs, assessment data and recommendations that are clear, targeted, and practical are the key to their usefulness in developing well-suited and effective interventions (Pei et al., 2013).

Positive asset building. The myriad of challenges experienced by children with FASDs can be so overwhelming that they cloud positive choices and prosocial behavior (Ryan & Ferguson, 2006b); and yet, positive reinforcement is vital to the development of intrinsic motivation, self-esteem and personal efficacy, character, and skill (Horne, 2014). It is recommended then that stakeholders make a concerted effort to build up positive assets in the children they work with rather than solely discouraging negative behaviors (Burgess & Streissguth, 1992). Positive asset building can be accomplished at home and school through the recognition of strengths and prosocial behavior as well as involvement in helpful, productive activities. Children with FASDs and their families often hear what they don't do well or what they fail to achieve (Pei et al., 2013). Thus, an emphasis on positive behaviors and assets can change the game for affected children and allow school personnel and allied professionals to make a lasting, constructive impression (Rogers-Adkinson & Stuart, 2007).

3. Home-school-community alliance

Among stakeholders in the present study, the value placed on the alliance between home, school, and community cannot be understated. Teachers, administrators, and allied professionals agreed that successful outcomes for children with FASDs are largely dependent on adult-child relationships, and that trust between home and school is vital in promoting consistent instruction and support across settings. Caregivers emphasized the need for their children to see them working together with teachers and allied professionals to reinforce behavior change and model consistent practice. Rather than adopting a *me-you* perspective, PCAP prevention specialists endeavor to create a mindset of *we,* communicating the importance of alliance in treatment and recovery. Indeed, an integrated, collaborative, and supportive network of individuals across settings was viewed as critical to the success of affected children and families and central to the crusade for improved process and activity across prevention, assessment and intervention.

Trusting partnerships. Trust denotes a confidence, reliance, surety—that someone or something will come through as expected. In order to establish trusting partnerships across settings, stakeholders must understand the vested interest of the other and the value each person brings to the collective work. To aid in the development of trust, participants recommended invested parties engage in frank and frequent conversation to ameliorate understanding of their respective roles and what each stakeholder offers the collaborative process (Job et al., 2013). With clarity comes confidence in the abilities of team members and importance of the collaboration. As one prevention specialist expressed: "… programs and strategies don't heal people, relationships do…" In trusting partnership, participants push for work with schools and community agencies to bring FASD to the forefront of public awareness and increase accessibility to supports and services, stating that best practice suggests stakeholders work in collaboration not isolation (Brown, 2004; Job et al., 2014).

The significance of trust between clients and advocates was also demonstrated through quilting with illustrations of physical closeness between people, hearts, interlocking hands, overlapping figures, and the use of words like "together," "trust," and "love." The quilting pieces provided evidence of the humanistic and relationship-based approaches of PCAP, illustrating the reality of our need for caring communities and partnerships (Job et al., 2014).

Improved adult-child relations. Experts have shown that few factors have a greater impact on a child's education and wellbeing than a caring relationship with a teacher. A student who feels a strong personal connection to his/her teacher displays more trust in adult relationships, shows greater motivation and engagement in learning, behaves better in class, demonstrates superior prosocial skills, and achieves higher academically (Baker, 2006; Birch & Ladd, 1998; Gregory & Ripski, 2008; Howes & Ritchie, 2002; Rimm-Kaufman & Sandilos, 2015; Wentzel, 1997, 2010; Zakrzewski, 2012). Teacher and allied professional groups identified individual interactions with students as having a major impact on learning, achievement, self-efficacy, and personal identity (Poth et al., 2013; Job et al., 2013). Affected children often face considerable difficulty with little support and so a caring, connected teacher, mentor or advocate can make a significant difference. Participants identified several activities helpful in the development of positive relationships between children with FASDs and individuals who work with them including getting to know students on a personal level, curtailing negative stereotypes, recognizing positive behaviors, integrating choice with expectations, and reflecting on experiences with care (Poth et al., 2014; Zakrzewski, 2012).

Healthy identity. Allowing children with FASDs the freedom to be who they are helps to build their personal identity. Stakeholders committed to the care and education of children have a responsibility to bolster their self-concept and identity through recognition of values, needs, capabilities, and interests and helping children to identify these things in themselves (Lindstrom et al., 2007; Poth et al., 2014; Ryan & Ferguson, 2006b). One way to achieve this successfully with affected children is for school personnel and allied professionals to focus on the person rather than the disability. Narrowing attention to a child's disability without regard for personal, familial, and environmental factors can lead us to miss core qualities needing guidance and support. Stakeholders expressed mixed feelings about accessing cumulative records prior to interacting with students as the information within provides good detail but it can also darken their view of student potential (Pei et al., 2013). This feedback aligns with research in the identity literature that cautions professionals to read records and reports with a watchful eye so as to not form firm ideas that may interfere with one’s ability to be effective and receptive as this has been shown to impact child self-efficacy, confidence, and achievement—aspects that are key to the development of healthy self-concept and identity (Lindstrom et al., 2007; Pei et al., 2015).

4. Professional development

A growing number of teachers are recognizing shortfalls in knowledge and scope of practice related the learning, social, and behavioral difficulties of children with FASDs, and are calling for improved preparation to manage complex disabilities and increased opportunities for skill development during the course of their careers (Carpenter, 2011; Job et al., 2012; Pei at al., 2015). Findings highlight the realistic challenges faced by practitioners tasked with providing educational programming yet possessing inadequate knowledge. If teachers are to accommodate a variety of learning needs, it only makes sense that they would have the requisite knowledge to be effective in intervention planning and implementation (Ryan & Ferguson, 2006). Building capacity then should begin with FASD education in teacher preparation programs and recurrent professional development focused on evidence-based teaching and behavior management strategies unique to this specialized population (Poth et al., 2014).

Improved knowledge and skills. The paucity of FASD-specific learning opportunities within teacher education programs and subsequent in-service professional development initiatives is worrisome (Blackburn et al., 2009; Carpenter, 2011; Pei et al., 2015). The preparation, development, and support of teachers greatly affect student learning and achievement. A strong teacher is critical to student success, especially among children with special needs; and strong teachers come from sound teacher preparation programs (U.S. Department of Education, 2014). Therefore, it is logical to begin FASD education and functional knowledge at the ground floor including post-secondary coursework in common learning and behavioral challenges, intervention strategies, effective collaboration, monitoring of personal attitudes, developmentally appropriate practice for the whole child, and classroom management techniques for inclusive settings (Brownell & Pajares, 1999; Campbell, Gilmore & Cuskelly, 2003; Shippen, Crites, Houchins, Ramsey, & Simon, 2005). Practical work with students with complex needs has also been shown to be an integral part of teacher preparation, helping to alleviate anxiety, increase enthusiasm, and raise self-efficacy beliefs (Brady & Woolfson, 2008; Romi & Leyser, 2006). Lastly, it is recommended that attention be focused in practicum to the development of reflective practice wherein the exercise of monitoring conceptions and attitudes becomes a habitual part of the learning and teaching process (Pei et al., 2015).

In research with school personnel, caregivers, and allied professionals, a call for improved teacher preparation and professional development was heard loudly across all four roles. Looking back on their university years, teachers and allied professionals recalled little learning about FASD if any, which led to consternation and dismay when faced with the varied learning profiles of several affected students in the classroom. Administrators confirmed the need for in-services specific to FASD as the complicated presentation of the disorder makes it challenging for even the most seasoned professional to know what strategies will be effective and how to best address unique behavioral and social-emotional needs (Job et al., 2013). Caregivers seconded this recommendation, reporting that improved FASD education at the pre-service level is key to implementing effective, individualized interventions and collaborating with community advocates and families of affected children (Job et al., 2013).

In a related vein, participants expressed concerns with the language used and strategies suggested in psychological reports, noting that limited FASD knowledge and experience puts school personnel and allied professionals at a disadvantage from understanding complexities in the data and knowing how to implement recommendations effectively. These findings speak to the disconnect between knowledge and action. Without foundational knowledge, it can be challenging to understand assessment results, which negatively impacts strategy implementation in the classroom (Pei et al., 2013). Considering the limited time, resources, and support educators and allied professionals encounter on the job, it is imperative that they begin their careers as well informed and prepared as possible as this will serve to enhance the learning environment and create positive experiences for affected and non-affected children alike (Pei et al., 2013; Poth et al., 2014; Shade & Stewart, 2001).

Accurate beliefs. Mistaken beliefs or misunderstandings about children with FASDs may be due to a lack of relevant education, experience, resources, or confidence (Job et al., 2013). Despite limited FASD knowledge, caregivers reported that school personnel still seemed to hold firm, stereotyped beliefs about affected students and make assumptions based on incomplete or inaccurate information or past experiences with other students (Job et al., 2013). This is problematic as the literature demonstrates that attitudes and beliefs about certain student groups may be difficult for teachers to change once established (Tait & Purdie, 2000). For this reason, it is especially wise to explore and revisit stakeholders understanding of different disabilities and engage them in conversation about how these conceptions merge with education and change with experience. The idea here is the *reframing of practices*—a theme highlighted in this dissertation and defined as “changing negative attitudes and enhancing FASD knowledge and skills” (Job et al., 2013, p. 58). It is posited that reframing the beliefs, attitudes, and practices of a teacher or allied professional positions him/her in a better place to evaluate strategies, programs, resources, and supports, selecting those that will be most valuable to the affected child and produce the best overall outcome. Moving from a space of subjectivity to objectivity, and seeing the child as he/she *is* rather than how we *perceive* him/her to be.

Enhanced self-efficacy. The combination of knowledge, attitude, beliefs, and efficacy among teachers and allied professionals has been documented as critical in the successful education and care of affected children (Cook, Tankersley, Cook, & Landrum, 2000) with efficacy and attitude being particularly influential in the development of child identity, confidence, security, and worth (Bandura, 1997; Tait & Purdie, 2000). In focus group discussions with prevention specialists, participants noted that an significant part of their work relates to the increase of client self-efficacy, which is central her growth, development, and definition of self (Job et al., 2014). As such, the prevention worker’s own feelings of efficacy and usefulness are key, and should be nurtured and supported, viewing their role as essential to professional development and best practice.

5. *Research engagement*

The need for evidence-based practice in the area of FASD was a topic discussed solely with PCAP prevention workers. Nonetheless, it is important to the conversation of collaborative planning and integrated service delivery as best practice in these areas requires stakeholders be informed about advances in research and strategies and processes demonstrated to be effective with similar populations. Prevention specialists were emphatic in their support of community-based research and collaboration with researchers in activities that felt authentic and purposeful

(Atkinson et al., 2013; Job et al., 2014). Increased opportunity to network and partner with researchers was underscored as critical to the improved use of research and understanding of its value, and inclusion of evaluations for programs to increase evidence-based practice in the field (Job et al., 2014).

Stakeholders may be tempted to accept recommended interventions and strategies that come with strong anecdotal support; however, evidence-based practice remains the true measure of reliability and validity in the field of educational psychology. Circumventing evidence-based practice to save effort or time may decrease access to strategies of great benefit and hinder the learning and achievement of affected children (Bohjanen, Humphrey, & Ryan, 2009). Certainly, a top priority for stakeholders across school and community settings should be to stay current in the literature, engage in research and evidence-based practice, and share information about relevant materials and resources with colleagues and community partners (Job et al., 2014). This practice allows everyone to be on the same page and remain updated about new developments in the education and care of affected students.

Learning and achievement. Prevention specialists emphasized the importance of a strong research-base for FASD programs as it provides credibility to the work being accomplished and focuses concentration for future goals and endeavors (Job et al., 2014). PCAP participants also highlighted that the continual evaluation of services holds stakeholders accountable to professional development and research engagement for best practice, which in turn, increases confidence in the effectiveness of their services and improves client outcomes (Job et al., 2014). Although they revered research and best practice, PCAP members reported concerns with the time commitment for retrieval current research, stating that the busyness of their jobs makes it difficult to keep as updated as they would like (Job et al., 2014).

An advantage of continued research engagement is its contribution to the learning and achievement of affected children. Research provides a way for frontline workers to access new and improved strategies that have been tested and validated on like populations. This provides teachers, caregivers, specialists, and allied professionals a starting point for intervention planning and program design rather than guessing which strategies will work with which learning challenge. For example, the Parents and Children Together (PACT) program is an early intervention that provides in-home counseling and school and community support to improve behavior and emotional regulation, executive functioning, and parent effectiveness (Institute for Family Development, 2013). If these skill areas are a focus for another child and his/her family, it makes sense that stakeholders would connect with PACT service providers and use features of the program that have proven successful with other families. It is important to recognize that caregiver and professional reliance on untested methods and strategies can lead to unreasonable expectations for learning and achievement and place the child with an FASD in a vulnerable position if objectives are not realized (Bohjanen et al., 2009; Marder & Fraser, 2012; Simpson, 2005).

CHAPTER VI

DIRECTIONS IN RESEARCH AND PRACTICE

The significance of the studies contained in this dissertation is extensive: (a) FASD is an overwhelming, life-long disability currently outranking Autism Spectrum Disorders (ASD) and Down Syndrome in prevalence (SAMHSA, 2005, 2014b; MoFAS, 2010); (b) FAS is listed first among the common causes of developmental disability on the CDC's (2015) website; (c) the majority of children with FASDs receive instruction in general education inclusive classroom settings (Ryan & Ferguson, 2006a); (d) ongoing relationships are of primary importance for affected children and families and yet are not a part of "usual care" (McLean, McDougall, & Russell, 2014); and (e) teachers and allied professionals are limited in their knowledge and understanding of FASD which leaves them unprepared for the complex behaviors and learning challenges experienced in the classroom (Atkinson, 2012; Blackburn, 2009; Blackburn et al., 2010; Carpenter, 2011; Job et al., 2012; Job et al., 2013; Pei et al., 2015; Ryan & Ferguson, 2006a).

During the same time that there has been a plethora of attention directed at ASDs, research on evidence-based practices for children and youth with FASDs has been in short supply (Bohajen, Humphrey, & Ryan, 2009). Thus, affected children and their families have been unable to benefit from the social, political, and financial support afforded those affected by ASDs (Ryan & Chionnaith, 2006; Ryan & Ferguson 2006a, 2006b). Researchers denote disparities between ASD and FASD in early diagnosis, individualized and special services, and evidence-based procedures in educational programming (Baugh et al., 2011; Koren et al., 2003; Poth & Pei, 2012; Ryan & Chionnaith, 2006; Ryan & Ferguson, 2006a; Streissguth, 1997) as well as a paucity of training for teachers and supports for families. The lack of comparable services and resources despite similar numbers children places children with FASDs and their families at considerable risk (Streissguth, 1997).

The fifth and final objective was to delineate areas for future inquiry and advancement of research in the field. To this end, 4 topics are put forth for additional inquiry and discussion: *community-based research, professional development, visual and multi-methods,* and *model of collaborative planning and integrated service delivery.*

Community-based research

The importance of research in the area of FASD is greater than ever before, and community-based research appears a brilliant fit. Community-based participatory research (CBR) is a "collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each [stakeholder] brings" (Kellogg Health Scholars, 2006, para. 2). The approach is gaining recognition as a valuable tool in the study of sensitive and involved health and social issues with affected individuals and within concerned communities. CBR is a collaboration between researchers and participants where the objective is to inform action through improved knowledge on relevant topics with the goal of affecting positive social change and promoting health equity (Horowitz, Robinson, & Seifer, 2009; Kellogg Health Scholars, 2006). This dissertation provides support for a CBR, multi-method approach to FASD research where the aim is to enhance community awareness and inform policy, strategic planning, and programming (McCarty et al., 1999). This approach fulfills the call for increased involvement of parent and support staff (e.g., teachers, counselors, community advocates) in research, adding context and content missed by traditional methods. Through conversation and collaboration, the investigative process is improved as researchers learn *what* questions to ask and *how* to ask them. This communicates to stakeholders the value of their contributions and enhances the relevancy of research for the population of interest and larger community.

In the present dissertation, CBR also provided researchers with a unique experience, engaging with stakeholders in a more personal way and encouraging reflection on involvement and impact. The research team for these studies was composed primarily of graduate students with limited prior experience in community-based, qualitative research but plenty of enthusiasm to learn. In this way, researchers and participants were true partners, jointly leading and learning new ways to collaborate and investigate. This effort was central to the conversation of improving stakeholders' access to and utilization of research to inform their practice. Focus group and interview participants across studies defined networking with researchers as critical to stakeholder buy-in and use of evidence-based interventions and programs (Job et al., 2014; Poth et al., 2014). Prevention specialists suggest the creation of an FASD-specific research database to enhance information sharing and keep frontline workers and affected families up to date on the latest findings and suggested practices for prevention, assessment, and intervention. Increasing the facility, consistency, and timeliness with which stakeholders receive information may be the key to improving links between knowledge and action, and cultivating a culture of informed practice across FASD networks, community agencies, and frontline workers (Pei & Poth, 2009).

Professional development

When it comes to educating children with FASDs, teachers, administrators, and allied school-based professionals (e.g., teaching assistants, counselors, social workers, school psychologists, and instructional coaches) report their greatest concern as a lack of knowledge, skills, and experience to effectively manage affected children's diverse learning needs, emotions, and behavior (Carpenter, 2011; Job et al., 2012; Pei at al., 2015). This is due in large part to the shortage of FASD-specific learning opportunities within initial teacher education programs and subsequent in-service professional development activities (Blackburn et al., 2009, 2010; Carpenter, 2011; Pei et al., 2015; Poth et al., 2014), as an absence of familiarity with the learning and behavioral profiles of affected students leaves teachers unprepared and unarmed to integrate these unique learners in the classroom and guide students toward successful outcomes (Carpenter, 2011). A strong teacher is crucial to student success, especially among children with complex needs, and strong teachers come from solid, rigorous teacher preparation (U.S. Department of Education, 2014). However, as the number of affected children rises so does teachers' recognition of their limited understanding of FASDs and need for increased teaching and training. In the present research, a call for improved pre-service preparation and regular in-services for practicing professionals was voiced loudly across roles (Job et al., 2013; Pei et al., 2013; Poth et al., 2014). Reflecting on their postsecondary education, teachers and allied professionals remembered little to no mention of FASD—a glaring oversight considering the numerous affected children encountered in practice (Job et al., 2012; Job et al., 2013). Especially worrisome is that despite limited FASD knowledge, school personnel still seem to develop firm ideas about affected students' learning profiles, and that these perceptions are difficult to change. Misconceptions or misunderstandings may be due to a lack of relevant experience, resources, or confidence. As such, it is put forth that amelioration of 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 insecurity (Job et al., 2013).

Building school personnel capacity for inclusive education of affected students should begin with a comprehensive introduction to FASD at the pre-service level and continue with professional development that addresses specific learning challenges and behaviors. Administrators confirmed the necessity of ongoing professional development on FASD as the multifaceted presentation of the disorder makes for challenging instruction and accommodation, especially when one affected child is so different from the next (Job et al., 2013). Participants hypothesize that continuing education in this area will provide teachers and allied professionals with the knowledge and skills needed to recognize affected students, assess their unique learning needs, and tailor interventions to facilitate growth and achievement (Job et al., 2013). Caregivers endorsed this suggestion, relaying experiences with uninformed teachers that proved arduous and wearing when communicating needs and advocating for individualized interventions with individuals who failed to understand the complexity of their children's condition (Job et al., 2013). This proved no truer than in assessment where inadequate knowledge and experience put teachers and allied professionals at a disadvantage for understanding complexities in evaluation data and effective implementation of recommendations (Pei et al., 2013). Caregivers stressed the need for aware and interested school personnel to continue to familiarize themselves with all aspects of FASD (i.e., prevention, assessment, and intervention) through continuing education and research if the goal is supportive, responsive environments where affected children can learn and grow (Poth et al., 2014; Shade & Stewart, 2001).

The need for enhanced awareness and 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 teaching and learning, sharing relevant research, anecdotal information, materials, and resources. When all the significant players have a common understanding of the affected child's abilities and disabilities, a more collaborative process results, which allows stakeholders to communicate openly and work together to provide the consistency in environment needed to optimize the child's development and inclusion (McLean et al., 2014). In addition to the inclusion of FASD education in teacher preparation programs and professional development activities, it is proposed that school personnel engage in practical work with affected students which may serve to alleviate anxiety, increase skill, cultivate adaptability, and raise self-efficacy beliefs (Brady & Woolfson, 2008; Romi & Leyser, 2006). One suggestion is to have mentoring opportunities wherein student teachers and new hires shadow seasoned staff in classrooms with children with FASDs, learning effective strategies through observation, role-play, student-teacher interaction, and instruction (Job et al., 2013) as well as weekly or monthly round-table discussions where teachers can share strategies and resources. Inviting knowledgeable professionals in the community to the table is recommended for added support and professional development.

Visual and multi-methods

Given the uniqueness of the program and its effectiveness in supporting at-risk women and children, PCAP is no stranger to survey and questionnaire. However, participants report that these efforts often miss the core issues of their work, providing little impact and applicability. Prevention specialists were open to participating in research but sought greater connection with participation and daily work activities. Understanding central concerns in FASD is about experience as much as facts and figures with personal narratives and imagery just as rich in data and just as helpful in directing future action. This dissertation supports the use of a multi-method approach to FASD research, particularly the innovative integration of interview and visual data as a means of accessing the subjective and subconscious participant experience (Job et al., 2014; Atkinson et al., 2013). In an era where researchers are increasingly called to inform policy and social change, stories and images have the ability to reach a widespread audience, breaking through common resistance and perception to engage the emotional with the intellectual in receivers' understanding of FASD (Job et al., 2014; Weber, 2008). It is this emotional engagement that leads individuals toward greater awareness and connection with their learning and places information into a context relevant to their lives and the world around them (Moulton, 2008). Emotions drive decisions. Decisions drive action. Action drives change (The Communications Network, 2014).

The findings of this dissertation submit the use of visual methods in research with special populations, particularly where traditional methods have been unable to deliver results that are relevant and useful to participants and stakeholders. Multimethodology is desirable for research with FASD and other complex populations for several reasons: (1) multi-methods allow researchers to approach their subject(s) from multiple perspectives to capture a more holistic view of experiences and events (Creswell & Plano Clark, 2011; Greene, 2007); (2) a multi-method approach considers the different aspects of social research (e.g., cognitive, ecological, emotional) and takes a pragmatic stance to methodology, selecting the methods that best suit a particular aspect and will best answer the research questions (Greene, 2007; Morgan, 2014). For example, semi-structured focus group sessions matched well to our exploration of stakeholder experiences with assessment and intervention. Participants were better able to remember details of their varied experiences listening to others and learned new information to help in their work. Additionally, this method enabled facilitators to guide discussion and prompt participants to ensure responses were relevant and meaningful to the research questions and study objectives, which can be a limitation of survey-based investigation; (3) using more than one methodology allows for the triangulation of data, which aids researchers in their explanation of constructs and relationships to gather a clear picture of the study population and social world in which they live (Alzheimer Europe, 2009 Greene, 2007; Morgan, 2014); and (4) multimethodology fits appropriately with a CBR approach wherein conversation, collaboration, and relationships are of central importance. Multi-methods facilitate a more personal transmission of research findings through direct quotation, illustration and imagery, and video. These mediums are viewed as necessary for some populations and in certain situations in order to truly access and understand participants' thoughts, feelings, and experiences (Alzheimer Europe, 2009; Atkinson et al., 2013; Job et al., 2014).

As follows, it is reasoned that creative expression through quilting holds promise as an avenue for making sense of and expressing experience, especially among stakeholders whose work involves *emotional labor* (i.e., managing negative emotions while working so as to present a positive front to clients) (Hochschild, 1983) and for whom *emotional exhaustion* (i.e., feeling psychologically and emotionally drained from excessive, stressful job/personal demands) (Maslach, 1982) is a concern. In our study with PCAP workers, the integration of focus groups with quilting afforded researchers greater insight into the work of FASD prevention and how job demands and client factors impact the emotional and relational selves. A cognitively and emotionally taxing career, prevention specialists engaged immediately with an activity that allowed them to openly express their thoughts, feelings, hopes, and stresses. The combined value of the quilting exercise for researchers and participants suggests its potential usefulness with numerous other professionals and families working with and caring for children with complex disabilities. Through visual and traditional storytelling, community partners are able to see how the parts make up the whole (Weber, 2008) and contextualize the material they read to appreciate the real individuals behind it (Job et al., 2014). There remains much to learn about stakeholder perceptions, thoughts, feelings, and interactions. Future investigation that takes a holistic, multi-method approach to data gathering will help researchers to develop processes that facilitate smarter and more effective practice for professionals, better care and service for children and families, and a robust framework for research in the field.

Model of collaborative planning and service delivery

The major contribution of this dissertation is the development of a model of collaborative planning and integrated service delivery informed by current knowledge and practice and identified areas of weakness or limitation for service providers and affected children. Grounded in theory and guided by stakeholder experience, the model delineates the components and activities necessary for effective conversation and collaboration across multiple systems, and suggests a holistic, FASD-informed approach to care and education that recognizes the various systems of influence that must work together to effect change. It is imperative that researchers and program developers be aware of these networks of influence when designing interventions and delivering services as a coordinated, conversational, and collaborative course of action is the best way to bring about lasting holistic and systemic reform (Rogers-Adkinson & Stuart, 2007).

The model proposes a systematic way of joining families, school personnel, allied professionals, and community agencies in prevention, assessment, and intervention. An evaluation of current knowledge and practice in the field suggest specific areas of weakness and limitation in planning and service delivery including awareness, understanding, assessment, capacity, and evidence-based practice. With the goal of developing a useful and practical model for FASD programs and services, reported challenges and drawbacks were used to inform the objectives and activities of a more collaborative and integrated action and highlight potential outcomes for stakeholders and affected children as a result of this harmonized effort. I believe that the proposed model has the potential to advise future research and program development in the following ways:

1. Identify key stakeholders to be involved in planning and implementation of tailored academic and behavioral;
2. Conduct needs assessments with affected children, caregivers, school personnel, and allied professionals to ensure interventions are targeted and individualized;
3. Assess teacher and allied professional competency to carry out interventions and provide professional development based on identified areas of weakness and/or limitation as needed
4. Create a system of support where the responsibility of intervention monitoring and evaluation is shared;
5. Enhance the assessment to intervention process through regular communication between evaluators and classroom teachers;
6. Increase the capacity of school personnel and caregivers to advocate for necessary services, supports, and resources;
7. Foster consistency in the application of learning strategies and behavior management techniques between home and school;
8. Engage stakeholders in research and evidence-based practice through the creation of a central online database for articles, interventions, websites, curricula, materials, and resources.

Inclusion of families in service is key to the success of a coordinated system of care. When caregivers are educated about their child’s disability, they are more likely to advocate and engage in school processes. It is important to remember that the whole family will be touched by FASD and that they hold a unique position of influence in the life of the affected child (Kids Mental Health, 2009); therefore, it makes sense to ensure they are informed and involved. In a qualitative study of the effectiveness of a multidisciplinary family support team, Walker (2003) found that parents reported the greatest improvement in their child's behavioral and emotional well-being when working in partnership with practitioners and allied professionals wherein their opinions and concerns were sought out and taken seriously. Parents noted increased confidence in their capacity to discuss and negotiate support when educated about their child's deficits and developmental needs and provided options for care. This approach to treatment is consistent with the unique model of school-based mental and physical health services put forth by the Dallas Independent School District (DISD) in Dallas, Texas. A nationally-recognized program, the Youth and Family Centers (YFC) offer free or low-cost assessment, individual and family counseling, psychiatric evaluation and medication management, and medical services to DISD students and their families (Dallas Independent School District [DISD], 2015a). These centers are linked to the schools to facilitate referral and collaboration but also operate independently to provide families with a safe and confidential place to go for help. In 1995, the YFC was created through a partnership with the Dallas Mental Health & Mental Retardation Center and Parkland Health and Hospital System to promote physical and mental healthcare of children and their families, taking a whole child perspective in recognition of the importance of health and wellness in academic achievement (Dallas Independent School District [DISD], 2015b; Kochhar-Bryant, 2010).

Following the DISD-YFC framework, it is my goal to pilot an integrated healthcare center that offers families affected by FASD a safe and confidential place to go for help and research its effectiveness in reducing secondary disabilities and improving academic, behavioral, and emotional outcomes. Due to the sensitivity and stigma surrounding this diagnosis, many families do not seek help, which only serves to further the struggle of affected children and stress of caregivers, teachers, and allied professionals (Edmonton Fetal Alcohol Network, 2015). Additional barriers to care include limited understanding of the disabling condition and related dysfunction, poor coordination across agencies, small staff numbers and poor quality of care, lack of transportation, and systemic issues (Weist, 1997). These obstacles have long been a problem and do our affected children a disservice when left unchallenged. I recognize the need for an integrated service delivery model wherein children and youth with diagnosed or suspected FASDs can access assistance specific to their situation without having to visit numerous healthcare and/or community organizations, and schools can collaborate to share and receive information pertinent to assessment, programming, and intervention. The primary aim of a collaboration between education, public healthcare and mental health systems is to generate a prevention–assessment–intervention continuum and develop a full range of care (Weist, Axelrod Lowie, Flaherty, & Pruitt, 2001). This cooperative effort lessens the burden on caregivers to communicate relevant health data to schools and lowers the liabilities of teachers to provide care and information that is outside there scope of practice (Weist et al., 2001). I am confident that the idea for an integrated healthcare center would further our knowledge of FASD and provide important direction for support and intervention across all levels of functioning as well as offer guidance for a coordinated framework of care for other special populations and complex diagnoses.

The development of appropriate standards of care for FASD is fundamental to the discussion of best practice. Currently, no standards of care exist for FAS and its related disorders (Stratton et al., 1996). Diagnosis is complicated and resources are rare. Often, affected individuals qualify for services because of associated medical problems, functional deficits, or learning needs rather than their FAS diagnosis (Coles, 2003). Despite a common belief that specialized supports and resources are needed, the provision of such services has not been a priority for most providers and government agencies; thus, evaluation of effective programs and services for prevention and intervention remains in its early stages. Thankfully, advocacy efforts have been fruitful with government beginning to acknowledge the needs of this important population (Coles, 2003). It is my hope that continued conversation and collaboration will be the vehicles by which an integrated level of care becomes the standard for children with FASDs.

REFERENCES

Abel, E. L. (1998). *Fetal alcohol abuse syndrome.* New York, NY: Plenum Press.

Ackerman, M. E. (1998). *Fetal Alcohol Syndrome: Implications for educators.* ERIC Document Reproduction Service No. ED426560. Chatham, VA: Rivermont School Central Health.

Alber, R. (2011, April 8). Intervention for failing students: What matters most? Retrieved December 20, 2012 from http://www.edutopia.org/blog/what-matters-most-student-academic-intervention-rebecca-alber

Alberta Education. (2009). *Re: defining success: A teamwork approach to supporting students with FASD.* Edmonton, AB: Alberta Education, Learning and Teaching Resources Branch. Retrieved from http://education.alberta.ca/media/932737/redefining_final.pdf

Aliyu, M. H., Wilson, R. E., Zoorob, R., Chakrabarty, S., Alio, A. P., Kirby, R. S., & Salihu, H. M. (2008). Alcohol consumption during pregnancy and the risk of early stillbirth among singletons. *Alcohol, 42*(5), 369-374. doi: 10.1016/j.alcohol.2008.04.003

Alzheimer Europe. (2009, August 21). *The four main approaches: Types of research.* Retrieved August 23, 2015 from http://www.alzheimer-europe.org/Research/Understanding-dementia-research/Types-of-research/The-four-main-approaches

American Pregnancy Association. (2014, January). *Pregnancy and alcohol.* Retrieved June 22, 2015 from http://americanpregnancy.org/pregnancy-health/pregnancy-and-alcohol/

Anastasi, A., & Urbina, S. (1997). *Psychological testing*. Upper Saddle River, NJ: Prentice Hall.

Athanasakis, E., Karavasiliadou, S., & Styliadis, I. (2011). The factors contributing to the risk of sudden infant death syndrome. *Hippokratia: Quarterly Medical Journal, 15*(2), 127-131.

Atkins, M. S., Hoagwood, K. E., Kutash, K., & Seidman, E. (2010). Toward the integration of education and mental health in schools. *Administration and Policy in Mental Health and*

Mental Health Services Research, 37(1-2), 40-47. doi: 10.1007/s10488-010-0299-7

Ausband, L. (200). Qualitative research and quilting: advice for novice researchers. *The Qualitative Report, 11*, 764–770.

Baker, J. A. (2006). Contributions of teacher-child relationships to positive school adjustment during elementary school. *Journal of School Psychology, 44*, 211-229.

Bandura, A. (1997). *Self-efficacy: The exercise of control.* New York, NY: W.H. Freeman.

Banks, M. (2001). *Visual Methods in Social Research*. London: Sage Publications Ltd.

Barth, R. (2001). Research outcomes of prenatal substance exposure and the need to review policies and procedures regarding child abuse reporting. *Child Welfare, 80,* 275–297.

Baugh, L., Denys, K., Hutchison, M., Kully-Martens, K., Tamana, S., & LaFrance, M. A. (2011, November). *Translating research into practice*. Paper presented at the 2011 Alberta FASD Conference, Calgary, AB.

Benz, M., Lindstrom, L., & Yovanoff, P. (2000). Improving graduation and employment outcomes of students with disabilities: Predictive factors and student perspectives. *Exceptional Children, 66*, 509-529.

Bingol, N., Schuster, C., Fuchs, M., Iosub, S., Turner, G., Stone, R. K., & Gromisch, D. S. (1987). The influence of socioeconomic factors on the occurrence of fetal alcohol syndrome. *Advances in Alcohol & Substance Abuse*, 6,105-118.

Birch, S. H., & Ladd, G. W. (1998). Children's interpersonal behaviors and the teacher-child relationship. *Developmental Psychology, 34*(5), 934-946.

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,* 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.

Bohjanen, S., Humphrey, M., & Ryan, S. M. (2009). Left behind: Lack of research-based interventions for children and youth with Fetal Alcohol Spectrum Disorders. *Rural Special Education Quarterly, 28*(2), 32-38.

Borghese, N., & Cole, E. (1994). Psychoeducational recommendations: Perceptions of school psychologists and classroom teachers. *Canadian Journal of School Psychology, 10,* 70-87.

Brady, K., & Woolfson, L. (2008). What teacher factors influence their attributions for children's difficulties in learning? *British Journal of Educational Psychology, 78*(4), 527-544. doi: 10.1348/000709907X268570

British Columbia Centre of Excellence for Women's Heath. (2013). Why do girls and women drink alcohol during pregnancy? Information for service providers. Retrieved February 23, 2015 from http://bccewh.bc.ca/wp-content/uploads/2014/08/FASD-Sheet-1_Who-Drinks-Alcohol-during-Pregnancy.2013.pdf

Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design.* Cambridge, MA: Harvard University Press.

Brown, J. D. (2004). Family supports for children who have alcohol-related disabilities.

Developmental Disabilities Bulletin, 32, 44-61.

Brownell, M. T., & Pajares, F. (1999). Teacher efficacy and perceived success in mainstreaming students with learning and behaviour problems. *Teacher Education and Special Education, 22*, 154-164. doi: 10.1177/088840649902200303

Burd, L., Klug, M. G., Martsolf, J. T., & Kerbeshian, J. (2003). Fetal alcohol syndrome: Neuropsychiatric phenomics. *Neurotoxicology and Teratology, 25,* 697–705. doi: 10.1016/j.ntt.2003.07.014

Burgess, E. M., & Streissguth, A. P. (1992). Fetal Alcohol Syndrome and fetal alcohol effects: Principles for educators. *Phi Delta Kappan, 74,* 24–30.

Burt, E., & Atkinson, J. (2011). The relationship between quilting and wellbeing. *Journal of Public Health, 34,* 54-59.

Caley, L. M., Kramer, C., & Robinson, L. K. (2005). Fetal alcohol spectrum disorder. *The Journal of School Nursing, 21*, 139-146. doi: 10.1177/10598405050210030301

Campbell, J., Gilmore, L., & Cuskelly, M. (2003). Changing student teachers' attitudes towards disability and inclusion. Journal of Intellectual & Developmental Disability, 28 (4), 369–379. doi: 10.1080/13668250310001616407

Carmichael-Olson, H., Rudo-Stern, J., & Gendler, B. (2011). Supporting parents of children with fetal alcohol spectrum disorders, and young children with significant prenatal alcohol exposure. In R. E. Tremblay, M. Boivin, R. D. Peters, & R. G., Barr (Eds.), *Encyclopedia on early childhood development* (pp. 1-10). Montreal, QC: Centre of Excellence for Early Childhood Development and Strategic Knowledge Cluster on Early Child Development.

Carpenter, B. (2011). Pedagogically bereft: Improving learning outcomes for children with Foetal Alcohol Spectrum Disorders. *British Journal of Special Education, 38,* 37–43.

doi:10.1111/j.1467-8578.2011.00495.x

Casto, L. D. (2013, May). Back to the future: A look at FASD in Alaska—past, present & future: Accomplishments, challenges and lessons learned. Oral presented at the *Fetal Alcohol Spectrum Disorders: Best Practices in the Last Frontier Conference*, Anchorage, AK.

Center for Disease Control and Prevention. (2015, July 9). *Facts about developmental disabilities.* Retrieved August 18, 2015 from http://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html

Center for Disease Control and Prevention. (2014b, June). *Fetal alcohol spectrum disorders (FASDs): Diagnosis.* Retrieved December 24, 2014 from http://www.cdc.gov/ncbddd/fasd/diagnosis.html

Center for Disease Control and Prevention. (2014a, April). *Alcohol use in pregnancy.* Retrieved August 29, 2014 from http://www.cdc.gov/ncbddd/fasd/alcohol-use.html

Center for Disease Control and Prevention. (2005, February). *A 2005 message to women from the U.S. Surgeon General: Advisory on alcohol use in pregnancy.* Retrieved from http://www.cdc.gov/ncbddd/fasd/documents/surgeongenbookmark.pdf

Center for Early Childhood Mental Health Consultation. (n.d.). Factors that influence children's social and emotional development. Retrieved August 29, 2014 from http://ecmhc.org/tutorials/social-emotional/mod1_2.html

Cheramie, G., Goodman, B., Santos, V., & Webb, E. (2007). Teacher perceptions of psychological reports submitted for emotional disturbance eligibility. *Journal of Education and Human Development, 1,* 1-8.

Chudley, A. E., Conry, J., Cook, J. L., Loocke, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical*

Association Journal, 172, 1-21. doi: 10.1503/cmaj.1040302

Clark, E., Minnes, P., Lutke, J., & Ouellette-Kuntz, H. (2008). Caregiver perceptions of the community integration of adults with Foetal Alcohol Spectrum Disorder in British Columbia. *Journal of Applied Research in Intellectual Disabilities, 21*, 446-456. doi:10.1111/j.1468-3148.2007.00414.x

Coggins, T., Timler, G., & Olswang, L. (2007). Impact of prenatal alcohol exposure and maltreatment on the social communicative abilities of school-age children with Fetal Alcohol Spectrum Disorders. *Language, Speech, and Hearing Services in Schools, 38,* 117-127.

Coles, C. D. (2003, March). Individuals affected by Fetal Alcohol Spectrum Disorder (FASD) and their families: Prevention, intervention and support. *Encyclopedia on Early Childhood Development.* Retrieved from http://www.child-encyclopedia.com/sites/default/files/textes-experts/en/877/individuals-affected-by-fetal-alcohol-spectrum-disorder-fasd-and-their-families-prevention-intervention-and-support.pdf

Coles, C. D., Brown, R. T., Smith, I. E., Platzman, K. A., Erickson, S., & Falek, A., (1991). Effects of prenatal alcohol exposure at school age: Physical and cognitive development. *Neurotoxicology and Teratology, 13,* 357-367.

Connor, P., & Streissguth, A. (1996). Effects of prenatal exposure to alcohol across the lifespan. *Alcohol Health and Research World, 20,* 148-157.

Cook, B. G., Tankersley, M., Cook, L., & Landrum, T. J. (2000). Teachers' attitudes toward their included students with disabilities. *Exceptional Children, 67,* 115-135. doi: 10.1086/499755

Creswell, J. W. (2013). Qualitative inquiry & research design (3rd ed.). Thousand Oaks, CA: Sage.

Creswell, J. W. (2012). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research* (4th ed.). Boston, MA: Pearson.

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches (3rd ed.).* Thousand Oaks, CA, United States: Sage Publications.

Creswell, J. W., & Plano Clark, V. L. (2011). *Designing and conducting mixed methods research.* Los Angeles, CA: Sage

Dallas Independent School District. (2015). *Youth & Family Centers.* Retrieved September 23, 2015 from http://www.dallasisd.org/Page/1427

Dallas Independent School District. (2015). *History of the Youth & Family Centers.* Retrieved September 23, 2015 from http://www.dallasisd.org/Page/27209

Dickie, V. (2010). Experiencing therapy through doing: Making quilts. *Occupation, Participation, and Health, 31,* 209-215.

DualDiagnosis.org. (2015). *Alcohol abuse and pregnancy.* Retrieved May 14, 2015 from http://www.dualdiagnosis.org/alcohol-addiction/pregnancy/

Dugle, S. V., & Grigorenko, P. (2015). Fostering resilient characteristics in individuals with learning disabilities. *ICCTE Journal, 10*(1), 3-10.

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,* 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,* 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.

Edmonton Fetal Alcohol Network. (2015, August 26). *NOFAS statement on the stigma of FASD.* Retrieved September 27, 2015 from http://preventionconversation.org/2015/08/26/nofas-statement-on-the-stigma-of-fasd/

Emmel, N., & Clark, A. (2011). Learning to use visual methodologies in our research: A dialogue between two researchers. *Forum Qualitative Sozialforschung /Forum: Qualitative Social Research*, *12*, Art. 36.

Environics Research Group. (2006). *Alcohol use during pregnancy and awareness of fetal alcohol syndrome and fetal alcohol spectrum disorder: Results of a national survey, final report.* Retrieved June 22, 2015 from ap-ag-finalreport06_e.pdf

Ernst, C. C., Grant, T. M., Streissguth, A. P., & Sampson, P. D. (1999). Intervention with high-risk alcohol and drug-abusing mothers: II. Three-year findings from the Seattle model of paraprofessional advocacy. *Journal of Community Psychology, 27*, 19-38.

Exceptional Learners Associates. (2015). *Psychoeducational assessment: Our philosophy.* Retrieved March 22, 2015 from http://excelearners.com/services/psychoeducational-assessment/our-philosophy/

Federico, M. A., Herrold, W., & Venn, J. (1999). Helpful tips for successful inclusion. *Teaching Exceptional Children, 32*, 76-82.

Fletcher, J. M., Foorman, B. R., Boudousquie, A., Barnes, M. A., Schatschneider, C., & Francis, D. J. (2002). Assessment of reading and learning disabilities: A research-based intervention-oriented approach. *Journal of School Psychology, 40,* 27-63. doi: 10.1016/S0022-4405(01)00093-0

Fletcher, J. M., Francis, D. J., Shaywitz, S. E., Lyon, G. R., Foorman, B. R., Stuebing, K. K., & Shaywitz, B. A. (1998). Intelligent testing and the discrepancy model for children with learning disabilities. *Learning Disabilities Research & Practice, 13,* 186-203.

Flottman, R., Stewart, L., & Tayler, C. (2011). *Victorian early years learning and development framework evidence paper: Practice principle 7—Assessment for learning and development.* Victoria, Australia: University of Melbourne, Department of Education and Early Childhood Development. Retrieved from http://www.education.vic.gov.au/documents/childhood/providers/edcare/pracassess.pdf

Food and Drug Administration [FDA]. (1981). Surgeon General's advisory on alcohol and pregnancy. *FDA Drug Bulletin, 11*(2), 9-10.

Fox, L., Vaughn, B., Wyatte, M. L., & Dunlap, G. (2002). “We can’t expect other people to understand”: Family perspectives on problem behavior. *Exceptional Children, 68*, 437-450.

Gahagan, S., Telfair Sharpe, T., Brimacombe, M., Fry-Johnson, Y., Brenneman, G., Levine, R., Mengel, M., O’Connor, M., Paley, B., & Adubato, S. (2006). Pediatricians’ knowledge, training, and experience in the care of children: With fetal alcohol syndrome. *Pediatrics, 118,* e657-e668. doi: 10.1542/peds.2005-0516

Galman, S. A. C. (2009). The truthful messenger: Visual methods and representation in qualitative research in education. *Qualitative Research, 9*, 197-217.

Gass, C. (2014, March). *Ask the expert: FASD—the current relevance of an age-old problem.* Retrieved July 1, 2015 from http://fasdcenter.samhsa.gov/askTheExpert/Mar2014.aspx

Gearing, R. E., McNeill, T., & Lozier, F. A. (2005). Father development and fetal alcohol spectrum disorder: Developing best practices. Journal of FAS International, 3(e14), 1-11.

Gelb, K., & Rutman, D. (2011). A Literature review on promising approaches in substance use treatment and care for women with FASD. Victoria, BC: University of Victoria.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory*. Chicago, IL: Aldine.

Glenchur, K. (2012, November 1). *Understanding and preparing your child for psychoeducational testing.* Retrieved July 23, 2015 from http://www.greatschools.org/gk/articles/understanding-and-preparing-your-child-for-psychoeducational-testing/

Gould, L., Job, J., St. Arnault, D., Pei, J., & Poth, C. (2012). *Shaping the future of Fetal Alcohol Spectrum Disorder (FASD): Policy, practice, and research in Alberta.* Poster presented at the 5th Annual Educational Psychology Graduate Student Colloquium, Edmonton, AB.

Government of Alberta. (2013). *Alberta PCAP Council.* Retrieved July 2, 2015 from http://fasd.alberta.ca/alberta-pcap-council.aspx

Government of Alberta. (2008). *FASD 10-year strategic plan.* Retrieved from www.fasd-cmc.alberta.ca/uploads/1004/fasd10yrplanfinal86321.pdf

Grant, T., Ernst, C. C., Pagalilauan G., & Streissguth, A. P. (2003). Post-program follow-up effects of paraprofessional intervention with high-risk women who abused alcohol and drugs during pregnancy. *Journal of Community Psychology, 31*, 211-222.

Grant, T. M., Ernst, C. C., & Streissguth, A. P. (1996). An intervention with high-risk mothers who abuse alcohol and drugs: The Seattle Advocacy Model. *American Journal of Public Health, 86*, 1816-1817.

Grant, T. M., Ernst, C. C., & Streissguth, A. P. (1999). Intervention with high-risk alcohol and drug-abusing mothers: I. Administrative strategies of the Seattle model of paraprofessional advocacy. *Journal of Community Psychology, 27*(1), 1-18.

Grant, T. M., Ernst, C. C., Streissguth, A. P., Phipps, P., & Gendler, B. (1996). When case management isn't enough: A model of paraprofessional advocacy for drug- and alcohol-abusing mothers. *Journal of Case Management, 5*, 3-11.

Grant, T., Ernst, C., Streissguth, A., & Stark, K. (2005). Preventing alcohol and drug exposed births in Washington State: Intervention findings from three Parent-Child Assistance Program sites. *American Journal of Drug and Alcohol Abuse, 31*, 471-490. doi: 10.1081/ADA-200056813.

Grant, T. M., Streissguth, A. P., & Ernst, C. C. (2002). Intervention with alcohol- and drug-abusing mothers and their children: The role of the paraprofessional. *The Source: Newsletter of the National Abandoned Infants Assistance Resource Center, 11*, 5-26.

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

Greene, J. C. (2007). *Mixed methods in social inquiry.* San Francisco, CA: Jossey-Bass.

Gregory, A., & Ripski, M. (2008). Adolescent trust in teachers: Implications for behavior in the high school classroom. *School Psychology Review, 37*(3), 337-353.

Groth-Marnat, G. (2009). The five assessment issues you meet when you go to heaven. *Journal of Personality Assessment, 91,* 303-310. doi: 10.1080/00223890902935662

Hannigan, J. H., & Berman, R. F. (2000). Amelioration of fetal alcohol-related neurodevelopmental disorders in rats: Exploring pharmacological and environmental treatments. *Neurotoxicology & Teratology, 22,* 103-111.

Harding, A. (2015, January 27). Most fetal alcohol spectrum disorders go undiagnosed. *Consultant 360 for Pediatricians: A Peer-Reviewed Journal.* Retrieved August 7, 2015 from http://www.pediatricsconsultant360.com/story/most-fetal-alcohol-spectrum-disorders-go-undiagnosed

Harris, S. R., MacKay, L. L. J., & Osborn, J. A. (1995). Autistic behaviors in offspring of mothers abusing alcohol and other drugs: A series of case reports. *Alcoholism: Clinical and Experimental Research, 19,* 660-665. doi: 10.1111/j.1530-0277.1995.tb01564.x

Hartwig, K., Calleson, D., & Williams, M. (2006). *Developing and sustaining community-based participatory research partnerships: A skill-building curriculum—Unit 1.3: Ethics and CBPR.* Retrieved July 24, 2015 from https://depts.washington.edu/ccph/cbpr/u1/u13.php

Harvey, V. (1997). Improving the readability of psychological reports. *Professional Psychology: Research and Practice, 28,* 271-274. doi: 10.1037/0735-7028.28.3.271

Harvey, V. (2006). Variables affecting the clarity of psychological reports. *Journal of Clinical Psychology, 62,* 5-18. doi: 10.1002/jclp.20196

Health Canada. (2006). *It's your health: Fetal alcohol spectrum disorder.* Retrieved March 15, 2011 from http://www.hcsc.gc.ca/hl-vs/iyh-vsv/diseases-maladies/fasd-etcaf-eng.php

Health Council of Canada. (2011). *Alberta FASD Cross-Ministry Committee (FASD-CMC).* Retrieved on March 3, 2013 from http://innovation.healthcouncilcanada.ca/innovation-practice/alberta-fasd-cross-ministry-committee#

Healthy Child Manitoba (2010). *What early childhood educators and caregivers need to know about Fetal Alcohol Spectrum Disorders (FASDs).* Retrieved from: http://www.gov.mb.ca/healthychild/fasd/fasdearly_en.pdf

Herz, R. (2013). Nurturing resiliency among adolescents with emotional and behavioral disturbances (EBD) in a special education setting. *Electronic Theses and Dissertations.* Paper 21. Retrieved June 10, 2015 from http://scholarworks.uni.edu/cgi/viewcontent.cgi?article=1021&context=etd

Hochschild, A. R. (1983). *The managed heart: Commercialization of human feeling.* Berkeley, CA, United States: University of California Press.

Horne, V. (2014, March 13). What are the benefits of positive reinforcement in kids? Retrieved August 12, 2015 from http://www.livestrong.com/article/498167-what-are-the-benefits-of-positive-reinforcement-in-kids/

Horowitz, C. R., Robinson, M., & Seifer, S. (2009). Community-based participatory research from the margin to the mainstream: Are researchers prepared? *Circulation, 119*, 2633-2642. doi: 10.1161/Circulationaha.107.729863

Howell, K. K., Lynch, M. E., Platzman, K. A., Smith, G. H., & Coles, C. D. (2006). Prenatal alcohol exposure and ability, academic achievement, and school functioning in adolescence: A longitudinal follow-up. *Journal of Pediatric Psychology, 31,* 116-126. doi: 10.1093/jpepsy/jsj029

Howes, C. & Ritchie, S. (2002). A matter of trust: Connecting teachers and learners in the early childhood classroom. New York, NY: Teachers College Press.

Idrus, N. M., & Thomas, J. D. (2011). Fetal Alcohol Spectrum Disorders: Experimental treatments and strategies for intervention. *Alcohol Research & Health, 34*(1), 76-85.

Institute for Family Development. (2013). *Parents and children together—PACT.* Retrieved May 16, 2015 from http://www.institutefamily.org/programs_PACT.asp

Iyasu, S., Randall, L. L., Welty, T.K., Risk factors for sudden infant death syndrome among Northern Plains Indians. *JAMA, 288*(21); 2717-2723.

Jimerson, S. R., Sharkey, J. D., Nyborg, V., & Furlong, M. J. (2004). Strength-based assessment and school psychology: A summary and synthesis. *The California School Psychologist, 9,* 9-19.

Jirikowic, T., Gelo, J., & Astley, S. (2010). Children and youth with fetal alcohol spectrum disorders: Summary of intervention recommendations after clinical diagnosis. *Intellectual and Developmental Disabilities, 48*, 330-344. doi: 10.1352/1934-9556-48.5.330

Job, J., O'Riordan, T., & Taylor, L. (2012). *Capturing the multifaceted and complex nature of work with individuals with FASDs: Practical guidelines for weaving quilting into community-based research.* Oral presentation at the Second European Conference on FASD, Barcelona, Spain.

Job, J., Pasula-Carter, B., Brandell, D., Pei, J., Poth, C., & Macnab, J. (2011, January). Toward better collaboration in the education of students with fetal alcohol spectrum disorders: Perspectives of teachers, administrators, caregivers, and allied professionals. *Hawaii International Conference on Education*, Honolulu, Hawaii.

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, 38-64.

Johnston, A. D. (2013, October 3). Women, we've got to talk about our drinking. *The Guardian.* Retrieved from http://www.theguardian.com/commentisfree/2013/oct/03/women-got-to-talk-about-drinking

Jonsson E., Salmon A., & Warren K. R. (2014). The international charter on prevention of fetal alcohol spectrum disorder. *The Lancet Global Health, 2*(3), e135 - e137. doi: 10.1016/S2214-109X(13)70173-6

Jones, C. (2013, March). *Keeping up with the flow: Why Feedly changes the game.* Retrieved December 22, 2015 from http://sourcepov.com/category/collaboration/

Jones, C. (2011, October). *The divergence of thought in science and philosophy: Could "complexity" be new common ground?* Retrieved August 29, 2014 from http://sourcepov.com/category/philosophy/

Jones S, & Telenta J. (2012). What influences Australian women to not drink alcohol during pregnancy? *Australian Journal of Primary Health, 18*, 68–73. doi: 10.1071/PY10077

Kalberg, W., & Buckley, D. (2007). FASD: What types of intervention and rehabilitation are useful? *Neuroscience and Biobehavioral Reviews, 31,* 278-285. doi: 10.1016/j.neubiorev.2006.06.014

Kellogg Health Scholars. (2006). *Community track*. Retrieved on August 15, 2015 from http://www.kellogghealthscholars.org/about/community.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. doi: 10.1016/S0892-0362(99)00073-2

Kids Mental Health. (2009). *Family therapy for children with behavioral disorders.* Retrieved

September 29, 2015 from http://www.kidsmentalhealth.org/family-therapy-for-children-with-behavioral-disorders/

Klin, A., Saulnier, C. D., Tsatsanis, K. D., & Volkmar, F. R. (2005). Clinical evaluation in autism spectrum disorders: Psychological assessment within a transdisciplinary framework. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (3rd ed.). Hoboken, NJ: John Wiley & Sons.

Knoetze, J., & Vermoter, C. (2007). Communication of psycho-educational assessment results: Remedial teachers' reading of assessment reports. *South African Journal of Education, 27,* 1-18.

Kochhar-Bryant, C. (2010). *Effective collaboration for educating the whole child.* Thousand Oaks, CA: Corwin.

Kodituwakku, P. W. (2007). Defining the behavioral phenotype in children with fetal alcohol spectrum disorders: A review. *Neuroscience and Biobehavioral Reviews, 31*, 192-201.

Kodituwakku, P. W., & Kodituwakku, E. L. (2011). From research to practice: An integrative framework for the development of interventions for children with fetal alcohol spectrum disorders. *Neuropsychology Review, 21*, 204-223. doi: 10.1007/s11065-011-9170-1

Koelsch, L. E. (2008). *Unlabeled sexual experiences: Quilting stories and reenvisioning discourses.* (Doctoral dissertation). Miami University, Miami, Florida, United States.

Koren, G., Nulman, I., Chudley, A. E., & Loocke, C. (2003). Fetal alcohol spectrum disorder. *Canadian Medical Association Journal, 169*, 1181-1185. doi: 10.1097/00007691-200304000-00001

Krueger, R. A., & Casey, M. A. (2000). *Focus groups: A practical guide for applied research*. Thousand Oaks, CA: Sage Publications.

Leonardson, G. R., & Loudenburg, R. (2003). Risk factors for alcohol use during pregnancy in a multistate area. *Neurotoxicology & Teratology, 25*, 651-658.

Leslie, M., & Roberts, G. (2001). Enhancing Fetal Alcohol Syndrome (FAS)-related intervention at the *Prenatal and Early Childhood Stages Conference* in Ottawa, Ontario.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA, United States: Sage Publications.

Lindstrom, L., Paskey, J., Dickinson, J., Doren, B., Zane, C., & Johnson, P. (2007). Voices from the field: Recommended transition strategies for students and school staff. *The Journal for Vocational Special Needs Education, 29*, 4-15.

Lupton, C., & Harwood, R. (2004). Cost of fetal alcohol spectrum disorders. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics, 127C*(1), 42-50.

Malbin, D. (2002). *Trying differently rather than harder: Fetal alcohol spectrum disorders: Second edition.* Portland, OR: FASCETS.

Malbin, D. V. (2004). Fetal alcohol spectrum disorder (FASD) and the role of family court judges in improving outcomes for children and families. *Juvenile and Family Court Journal, 55*(2), 53-63. doi: 10.1111/j.1755-6988.2004.tb00161.x

Malisza, K. L., Allman, A. A., Shiloff, D., Jakobson, L., Longstaffe, S., & Chudley, A. E. (2005). Evaluation of spatial working memory function in children and adults with Fetal Alcohol Spectrum Disorders: A functional magnetic resonance imaging study. *Pediatric Research, 58,* 1150-1157. doi: 10.1203/01.pdr.0000185479.92484.a1

Marder, T., & Fraser, D. (2012). Evidence-based practice for special educators teaching students with autism. *New Horizons for Learning, 10*(2). Retrieved from http://education.jhu.edu/PD/newhorizons/Journals/specialedjournal/MarderandFraser

Maslach, C. (1982). *The burnout: The cost of caring*. Engelwood Cliffs, NJ: Prentice Hall.

Mastoras, S., Climie, E., McCrimmon, A., & Schwean, V. (2011). A C.L.E.A.R. approach to report writing: A framework for improving the efficacy of psychoeducational reports. *Canadian Journal of School Psychology, 26,* 127-147. doi: 10.1177/0829573511409722

May, P. A., Baete, A., Russo, J., Elliott, A. J., Blankenship, J., Kalberg, W. O., Buckley, D., Brooks, M., Hasken, J., Abdul-Rahman, O., Adam, M. P., Robinson, L. K., Manning, M., & Hoyme, H. E. (2014). *Pediatrics, 134*(5), 855-866. doi:10.1542/peds.2013-3319

May, P. A., & Gossage, J. (2011). Maternal risk factors for fetal alcohol spectrum disorders: Not as simple as it might seem. *Alcohol Research & Health, 34*(1), 15-26.

May, P. A., & Gossage, J. (2001). Estimating the prevalence of fetal alcohol syndrome: A summary. *Alcohol Research & Health, 25*, 159-167.

May, P. A., Gossage, J. P., Kalberg, W. O., Robinson, L. K., Buckley, D., Manning, M., Hoyme, H. E. (2009). Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Developmental Disabilities Research Review, 15*(3), 176-192. doi: 10.1002/ddrr.68

May, P. A., Gossage, J. P., Brooke, L. E., Snell, C. L., Marais, A.-S., Hendricks, L. S., et al. (2005). Maternal risk factors for fetal alcohol syndrome in the Western Cape Province of South Africa: A population-based study. *American Journal of Public Health*, 95, 1190-1199.

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*, 561-577.

McLean, S., McDougall, S., & Russell, V. (2014, December). Supporting children living with fetal alcohol spectrum disorders: Practice principles. *Child-Family-Community Australia Practitioner resource.* Retrieved from https://aifs.gov.au/cfca/publications/supporting-children-living-fetal-alcohol-spectrum-disor

Means, B., Padilla, C., DeBarger, A., & Bakia, M. (2009). Implementing data-informed decision making in schools—teacher access, supports and use. Report prepared for U.S. Department of Education, Office of Planning, Evaluation and Policy Development. Prepared by SRI International, Menlo Park, CA. Retrieved from http://www.sri.com/work/publications/implementing-data-informed-decision-making-schools-teacher-access-supports-and-use

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.

Meurk, C. S., Broom, A., Adams, J., Hall, W., & Lucke, J. (2014). Factors influencing women's decisions to drink alcohol during pregnancy: Findings of a qualitative study with implications for health communication. *BMC Pregnancy and Childbirth, 14*, 246-255. doi: 10.1186/1471-2393-14-246

Meyer-Leu, Y., Lemola, S., Daeppen, J.-B., Deriaz, O., & Gerber, S. (2011). Association of moderate alcohol use and binge drinking during pregnancy with neonatal health. *Alcoholism: Clinical and Experimental Research, 35*(9), 1669-1677.

Millar, J. A., Thompson, J., Schwab, D., Hanlon-Dearman, A., Goodman, D., Koren, G., & Masotti, P. (2014). Educating students with FASD: Linking policy, research and practice.

Journal of Research in Special Educational Needs, 1-15. doi: 10.1111/1471-3802.12090

Milne, D. (2014). The lived experience of adoptive mothers raising children diagnosed with fetal alcohol spectrum disorder: A phenomenological study. (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses. (Accession Order No. AAT 3665493).

Moore, T., Ochiltree, G., & Cann, W. (2002). BEST START effective intervention programs: Examples of effective interventions, programs and service models. Melbourne, Australia: State of Victoria, Department of Human Services. Retrieved from https://www.eduweb.vic.gov.au/edulibrary/public/beststart/effective_programs_project-1002v1.2.pdf

Morgan, D. L. (2014). *Integrating qualitative & quantitative methods: A pragmatic approach.* Los Angeles, CA: Sage.

Moulton, J. (2008, January 30). *Emotional engagement in education, part one: Should teachers care about student apathy?* Retrieved September 11, 2015 from http://www.edutopia.org/emotional-engagement-education-part-one

Murray, M., Curran, E., & Zellers, D. (2008). Building parent/professional partnerships: An innovative approach for teacher education. *The Teacher Educator, 4*3, 87-108. doi: 10.1080/08878730701838819

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.

National Wraparound Initiative. (2014). *Resource guide to wraparound.* Retrieved April 23, 2015 from http://nwi.pdx.edu/NWI-book/

Nota Bene Consulting Group & BCCEWH. (2013a). Community/system outcomes:

Community partners make FASD-informed shifts in practice. In *Evaluation of FASD prevention and FASD support programs.* Vancouver, BC: British Columbia Centre of Excellence for Women's Health.

Nota Bene Consulting Group & BCCEWH. (2013b). FASD-informed practice. In *Evaluation of FASD prevention and FASD support programs.* Vancouver, BC: British Columbia Centre of Excellence for Women's Health.

O'Connor, M. J., Frankel, F., Paley, B., Schonfeld, A. M., Carpenter, E., Laugeson, E. A., & Marquardt, R. (2006). A controlled social skills training for children with fetal alcohol spectrum disorders. *Journal of Consulting and Clinical Psychology, 74*, 639-648.

Olson, H. C., Oti, R., Gelo, J., & Beck, S. (2009). "Family matters:" Fetal alcohol spectrum disorders and the family. *Developmental Disabilities Research Reviews*, 15, 235-249. doi: 10.1002/ddrr.65

Olson, H., Quamma, J., Brooks, A., Lehman, K., Ranna, M., & Astley, S. (2005). Efficacy of a new model of behavioral consultation for families raising school-aged children with FASD and behavior problems. *Alcoholism: Clinical and Experimental Research, 29*, 172-189.

OMHSAS Bureau of Children's Behavioral Health Services. (2011, November). A call to action—Fetal alcohol spectrum disorders: Awareness, identification and intervention for children in Pennsylvania. Harrisburg, PA: Pennsylvania Department of Public Welfare.

Ospina, M., & Dennett, L. (2013). *Systematic review on the prevalence of Fetal Alcohol Spectrum Disorders.* Edmonton, AB: Institute of Health Economics.

O'Sullivan, E., & Taylor, M. (2004) *Learning towards an ecological consciousness.* New York, NY: Palgrave Macmillan.

PACER Center. (2015). *Evaluation: What does it mean for your child? PACER Center ACTion information sheets.* Retrieved July 12, 2015 fro http://www.pacer.org/parent/php/PHP-c2.pdf

Paley, B., & O’Connor, M. J. (2011). Behavioral interventions for children and adolescents with Fetal Alcohol Spectrum Disorders. *Alcohol Research & Health, 34*(1), 64-75.

Paley, B., & O’Connor, M. J. (2009). Interventions for children with fetal alcohol spectrum disorders: Treatment approaches and case management. *Developmental Disabilities Research Reviews, 15,* 258- 267. doi: 10.1002/ddrr.67

Paley, B., & O’Connor, M. J. (2007). Neurocognitive and neurobehavioral impairments in individuals with fetal alcohol spectrum disorders: Recognition and assessment. *International Journal of Disability and Human Development, 6,* 127-142.

Paley B., O’Connor, M. J., Baillie, S. et al. (2009). Integrating case topics in medical school curriculum to enhance multiple skill learning: Using fetal alcohol spectrum disorders as an exemplary case. *Academic Psychiatry, 33,* 143-148. doi: 10.1176/appi.ap.33.2.143

Parent-Child Assistance Program (PCAP). (2010). *A model of effective community intervention with high-risk families.* Seattle, WA: University of Washington. Retrieved from http://depts.washington.edu/pcapuw/PCAP_E-Manual_10_1_10.pdf

Patton. M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Patton, M. Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). Newbury Park, CA: Sage.

Pei, J., Denys, K., Hughes, J., & Rasmussen, C. (2011). Mental health issues in fetal alcohol spectrum disorder. *Journal of Mental Health, 20,* 438-448. doi:

10.3109/09638237.2011.577113

Pei, J., Job, J., Poth, C., O'Brien-Langer, A., & Tang, W. (2015). Enhancing learning environments for students affected by Fetal Alcohol Spectrum Disorders: An exploratory study of Canadian pre-service teacher knowledge and conceptions. *Journal of Education and Training Studies, 3*(5), 134-143.

Pei, J., Job, J. M., Poth, C., & Atkinson, E. (2013). Assessment for intervention of children with fetal alcohol spectrum disorders: Perspectives of classroom teachers, administrators, caregivers, and allied professionals. *Psychology, 4*(3A), 325-334. doi: 10.4236/psych.2013.43A047

Pei, J., & Poth, C. (2009). *Effective strategies for bridging the communication gap in service delivery for FASD individuals*. Presented at the 2009 Alberta FASD Conference, Edmonton, AB.

Pelech, W., Pei, R. J., Poth, R. C., Atkinson, E., Job, J., McCallum, K., & Wyper, K. (2013, January 31). Fetal Alcohol Spectrum Disorder (FASD): Year 5 evaluation of the Government of Alberta's FASD 10 year strategic plan. Retrieved May 14, 2014 from www.research4children.org/data/.../Outcome1bdocdocx.docx

Pink, S. (2007). *Doing visual ethnography.* London, England: Sage Press.

Pires, S. A. (2002). *Building systems of care: A primer.* Washington, DC: National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center. Retrieved from http://gucchd.georgetown.edu/products/PRIMER_Part1.pdf

Poole, N. A. (2008). *Fetal Alcohol Spectrum Disorder (FASD) Prevention: Canadian Perspectives.* Retrieved from http://www.phac-aspc.gc.ca/fasd-etcaf/index-eng.php

Poole, N., Nathoo, T., & Hache, A. (2013). Community-driven alcohol policy and foetal alcohol spectrum disorder prevention: Implications for Canada's north? *International Journal of Circumpolar Health, ICCH15 Proceedings, 72* (S1), 250-251. Retrieved from http://www.circumpolarhealthjournal.net/public/journals/32/chs/CHS_2013_10.pdf

Popova, S., Stade, B., Lange, S., Bekmuradov, D., & Rehm, J. (2012). *Economic impact of fetal alcohol syndrome (FAS) and fetal alcohol spectrum disorders (FASD): A systematic literature review.* Toronto, ON: Centre for Addiction and Mental Health. Retrieved from https://knowledgex.camh.net/reports/Documents/economic_impact_fas_litreview12.pdf

Popova, S., Stade, B., Bekmuradov, D., Lange, S., & Rehm, J. (2011). What do we know about the economic impact of fetal alcohol spectrum disorder? A systematic literature review. *Alcohol and Alcoholism, 46*(4), 490-497. doi: http://dx.doi.org/10.1093/alcalc/agr029

Poth, C., & Pei, J. (2012). *Fetal alcohol spectrum disorder (FASD) 10-year strategic plan: A summary of the Year Five evaluation project.* Unpublished manuscript. University of Alberta, Edmonton, Alberta.

Poth, C., Pei, J., Job, J. M., & Wyper, K. (2014). Toward intentional, reflective, and assimilative classroom practices with students with FASD. *The Teacher Educator, 49*(4), 247-264. doi: 10.1080/08878730.2014.933642

Public Health Agency of Canada. (2012). *Fetal Alcohol Spectrum Disorder (FASD): A framework for action.* Retrieved from: http://www.phac-aspc.gc.ca/publicat/fasd-fw-etcaf-ca/framework-eng.php

Public Health Agency of Canada. (2011). *Assessment and diagnosis of FASD among adults: A national and international systematic review.* Retrieved from: http://www.phacaspc.gc.ca/fasd-etcaf/index-eng.php

Purdey, C. D. (2006). *Children diagnosed with fetal alcohol spectrum disorder: A student-based needs assessment.* Retrieved from: http://dtpr.lib.athabascau.ca/action/download.php?filename=caaploi/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. doi: 10.1097/01.alc.0000175040.91007.d0

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.

Rasmussen, C., & Bisanz, J. (2009). Executive functioning in children with fetal alcohol spectrum disorders: Profiles and age-related differences. *Child Neuropsychology, 15*(3), 201-215.

Rasmussen, C., Kully-Martens, K., Denys, K., Badry, D., Henneveld, D., Wyper, K., & Grant, T. (2012). The effectiveness of a community-based intervention program for women at-risk for giving birth to a child with Fetal Alcohol Spectrum Disorder (FASD). *Community Mental Health Journal, 48,* 12-21. doi: 10.1007/s10597-010-9342-0

Reddy, L., & Newman, E. (2009). School-based programs for children with emotional disturbance: Obstacles to program design and implementation and guidelines for school practitioners. *Journal of Applied School Psychology, 25,* 169-186. doi: 10.1080/15377900802486971

Rhee, S., Furlong, M., Turner, J., & Harari, I. (2001). Integrating strength-based perspectives in psychoeducational evaluations. *The California School Psychologist, 6,* 5-17.

Riggie, J. L., & Xu, T. (2013). Supporting individuals with fetal alcohol spectrum disorders: A summary of effective practices. *Physical Disabilities: Education and Related Services, 32*(2), 43-89. doi: 10.14434/pders.v32i2.12996

Roebuck, T. M., Mattson, S. N., & Riley, E. P. (1999) Behavioural and psychosocial profiles of alcohol-exposed children. *Alcoholism: Clinical and Experimental Research, 23*, 1070-1076. doi: 10.1111/j.1530-0277.1999.tb04227.x

Rogers-Adkinson, D. L., & Stuart, S. K. (2007). Collaborative services: Children experiencing neglect and the side effects of prenatal alcohol exposure. Language, Speech, and Hearing Services in Schools, 38, 149-156. doi: 10.1044/0161-1461(2007/015)

Romi, S., & Leyser, Y. (2006). Exploring inclusion and pre-service training needs: A study of variables associated with attitudes and self-efficacy beliefs. *European Journal of Special Needs Education, 21*(1), 85-105. doi: 10.1080/08856250500491880

Rose, G. (2001). *Visual methodologies: A guide to the interpretation of visual materials.* London, England: Sage Publications.

Rossman, R. B., & Ralllis, S. F. (1998). *Learning in the field: An introduction to qualitative research.* Thousand Oaks, CA: Sage.

Rubio, D. M., Kraemer, K. L., Farrell, M. H., & DAY, N. L. (2008). Factors associated with alcohol use, depression, and their co-occurrence during pregnancy. *Alcoholism: Clinical and Experimental Research, 32,* 1543-1551.

Ruiz, M. (2014, October). Why I drank while I was pregnant. *Cosmopolitan.* Retrieved from http://www.cosmopolitan.com/sex-love/news/a32292/why-i-drank-while-i-was-pregnant/

Rutman, D. (2013). Voices of women living with FASD: Perspectives on promising approaches in substance use treatment, programs and care. *First Peoples Child & Family Review,* *8*(1), 107-121.

Ryan, F. (2011, August 10). Our ‘drinking culture’ isn’t romantic, it’s killing us. *TheJournal.ie.* Retrieved from http://www.thejournal.ie/readme/column-our-‘drinking-culture’-isn’t-romantic-it’s-killing-us/

Ryan, S. M. (2006). Instructional tips: Supporting the educational needs of students with fetal alcohol spectrum disorders. *Teaching Exceptional Children Plus, 3*(2) Article 5. Retrieved from http://escholarship.bc.edu/education/tecplus/vol3/iss2/art5

Ryan, S., & Chionnaith, M. N. (2006). On the spectrum: Similarities and differences between students with fetal alcohol spectrum disorders and autism spectrum disorders in Ireland. *Journal of International Special Needs Education, 9,* 43-52.

Ryan, S., & Ferguson, D. L. (2006). On, yet under, the radar: Students with fetal alcohol syndrome disorder. *Exceptional Children, 72,* 363- 365.

Ryan, S., & Ferguson, D. L. (2006). The person behind the face of fetal alcohol spectrum disorder: Student experiences and family and professionals’ perspectives on FASD. *Rural Special Education Quarterly, 25,* 32-40.

Sampson, P. D., Streissguth, A. P., Bookstein, F. L., Little, R. E., Clarren, S. K., Dehaene, P., & Graham Jr., J. H. (1997). Incidence of fetal alcohol syndrome and prevalence of alcohol-related neurodevelopmental disorder. *Teratology, 56*, 317-326.

Savenye, W. C., & Robinson, R. S. (2003). Qualitative research issues and methods: An introduction for educational technologists. In D. H. Jonassen (Ed.), *Handbook of research on educational communications and technology* (2nd ed., pp. 1045-1071).

Scott, T. M., & Eber, L. (2003). Functional assessment and wraparound as systemic school processes: Primary, secondary, and tertiary systems examples. *Journal of Positive*

Behaviour Interventions, 5, 131-143.

Seligman, M., Linley, P., & Joseph, A. (2004). *Positive psychology in practice.* Hoboken, NJ: Wiley.

Shade, R. A., & Stewart, R. (2001). General education and special education pre-service teachers' attitudes toward inclusion. *Preventing School Failure, 46*(1), 37-41. doi: 10.1080/10459880109603342

Shippen, M. E., Crites, S. A., Houchins, D. E., Ramsey, M. L., & Simon, M. (2005). Pre-service teachers' perceptions of including students with disabilities. *Teacher Education and Special Education, 28*(2), 92-99. doi: 10.1177/088840640502800202

Simpson, R. (2005). Evidence-based practices and students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 20*(3), 140-149.

Sokol, R. J., Delaney-Black, V., Nordstrom, B. (2003). Fetal alcohol spectrum disorder. *JAMA, 290*(22), 2996-2999.

Stade, B., Ali, A., Bennett, D., Campbell, D., Johnston, M., Lens, C. et al. (2009). The burden of prenatal exposure to alcohol: Revised measurement of cost, 2007. *Canadian Journal of Clinical Pharmacology, 16*, e91-e102.

Stade, B., Ungar, W. J., Stevens, B. Beyens, J., & Koren, G. Cost of fetal alcohol spectrum disorder in Canada. *Canadian Family Physician, 53*(8), 1303-1304.

Steinhausen, H. C., & Spohr, H. L. (1998). Long-term outcome of children with fetal alcohol syndrome: Psychopathology, behavior, and intelligence. *Alcoholism: Clinical & Experimental Research, 22*, 334-338.

Steinhausen, H., Willms, J., Metzke, C.W., & Spohr, H. (2003). Behavioural phenotype in foetal alcohol syndrome and foetal alcohol effects. *Developmental Medicine and Child*

Neurology, 45, 179-182. doi: 10.1111/j.1469-8749.2003.tb00927.x

Stratton, K. R., Howe, C. J., & Battaglia, F. C. (Eds.). (1996). *Fetal alcohol syndrome: Diagnosis, epidemiology, prevention, and treatment.* Washington, DC: Institute of Medicine, National Academy Press.

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., Barr, H. M., Kogan, J., & Bookstein, F. L. (1996). *Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE): Final report to the Centers for Disease Control and Prevention.* Seattle: University of Washington, Fetal Alcohol and Drug Unit.

Streissguth, A., Bookstein, F., Barr, H., Sampson, P., O'Malley, K., & Young, J. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics*, *25,* 228-238.

Streissguth, A. P., & Kanter, J. (1997). *The challenges of Fetal Alcohol Syndrome: Overcoming secondary disabilities.* Seattle, WA: University of Washington Press.

Streissguth, A.P., & O'Malley, K. (2000). Neuropsychiatric implications and long-term consequences of fetal alcohol spectrum disorders. *Seminars in Clinical Neuropsychiatry*, *5*(3), 177-190.

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.

Substance Abuse and Mental Health Services Administration: FASD Center for Excellence (2015). *Curriculum for addiction professionals: Levels 1 and 2*. Retrieved June 16, 2015 from http://fasdcenter.samhsa.gov/educationtraining/EducationTraining.aspx

Substance Abuse and Mental Health Services Administration: FASD Center for Excellence. (2014). FASD in Review: Review of the article 'Prevalence and characteristics of Fetal Alcohol Spectrum Disorders' by P. A. May et al. *Pediatrics, 134*(5), 855-866.

Substance Abuse and Mental Health Services Administration: FASD Center for Excellence. (2014). Fetal Alcohol Spectrum Disorders: The Basics. Retrieved August 18, 2015 from http://fasdcenter.samhsa.gov/educationTraining/FASDBASICS/FASDTheBasics.pdf

Substance Abuse and Mental Health Services Administration. (2014). *Results from the 2013 national survey on drug use and health: Summary of national findings*, NSDUH Series H-48, HHS Publication No. (SMA) 14-4863. Rockville, MD: Substance Abuse and Mental Health Services Administration.

Substance Abuse and Mental Health Services Administration. (2013). *Results from the 2012 national survey on drug use and health: Summary of national findings*, NSDUH Series H-46, HHS Publication No. (SMA) 13-4795. Rockville, MD: Substance Abuse and Mental Health Services Administration.

Substance Abuse and Mental Health Services Administration. (2004). *Results from the 2003 national survey on drug use and health: Summary of national findings*. NSDUH Series H-25, DHHS Publication No. (SMA) 04-3964. Rockville, MD: Substance Abuse and Mental Health Services Administration.

Tait, K., & Purdie, N. (2000). Attitudes toward disability: Teacher education for inclusive environments in an Australian university. *International Journal of Disability, Development, and Education, 47*(1), 25-38. doi: 10.1080/103491200116110

Terjesen, M. D., Jacofsky, M., Froh, J., & DiGiuseppe, R. (2004). Integrating positive psychology into schools: Implications for practice. *Psychology in the Schools, 41,* 163-172. doi: 10.1002/pits.10148

The Communications Network. (2014, August 11). *Emotional rescue.* Retrieved September 9, 2015 from http://www.comnetwork.org/2014/08/emotional-rescue/

Thorne, S. (2000). Data analysis in qualitative research. *Evidence Based Nursing, 31*, 68-70.

Timler, G. R., & Olswang, L. B. (2001). Variable structure/variable performance: Parent and teacher perspectives on a school-age child with FAS. *Journal of Positive Behavioral Interventions, 3*(1), 48-56.

U.S. Department of Education. (2014). *Improving teacher preparation: Building on innovation.* Retrieved August 13, 2015 from http://www2.ed.gov/documents/teaching/teacher-prep.pdf

van der Westhuizen, T. (n.d.). *The big pic principle.* Retrieved July 2, 2015 from http://biggerpicture.weebly.com/the-big-pic-principle.html

Walker, S. (2003). Multidisciplinary family support in child and adolescent mental health services. *Clinical Child Psychology & Psychiatry, 8*, 215-226.

Walker, M. J., Al-Sahab, B., Islam, F., Tamim, H. (2011). The epidemiology of alcohol utilization during pregnancy: An analysis of the Canadian Maternity Experiences Survey. *BMC Pregnancy and Childbirth*, *11*, 52-61. doi: 10.1186/1471-2393-11-52

Warren, K. R., Hewitt, B. G., & Thomas, J. D. (2011). Fetal Alcohol Spectrum Disorders:

Research challenges and opportunities. *Alcohol Research & Health, 34*(1), 4-14.

Washington, O., Moxley, D., & Garriott, J. (2009). The ‘telling my story’ quilting workshop: Innovative group work with older African American women transitioning out of homelessness. *Journal of Psychosocial Nursing, 47,* 42-52.

Waters, J. (2013). *Phenomenological research guidelines.* Retrieved March 11, 2015 from https://www.capilanou.ca/psychology/student-resources/research-guidelines/Phenomenological-Research-Guidelines/

Watson, S. M. R., Gable, R. A., & Tonelson, S. W. (2003). Students prenatally exposed to drugs and alcohol: A survey of school personnel preparation. *The Teacher Educator, 38*, 190-208. doi: 10.1080/08878730309555317

Watson, S. M. R., & Westby, C. E. (2003). Prenatal drug exposure: Implications for personnel preparation. *Remedial and Special Education, 24*, 204-214. doi: 10.1177/07419325030240040401

Weber, S. (2008). Chapter 5: Using visual images in research. In J. G. Knowles & A. L. Cole (Eds.), *Handbook of the arts in qualitative research: Perspectives, methodologies, examples, and issues* (pp. 41-54). London, England: Sage Press.

Weist, M. D. (1997). Expanded school mental health services: A national movement on progress. In T. H. Ollendick & T. J. Prinz (Eds.), *Advances in Clinical Child Psychology*, (vol.19, pp. 319-352). New York, NY: Plenum.

Weist, M. D., Axelrod Lowie, J., Flaherty, L. T., & Pruitt, D. (2001). Collaboration among the education, mental health, and public health systems to promote youth mental health. *Psychiatric Services, 52*(10), 1348-1351. doi: 10.1176/appi.ps.52.10.1348

Wentzel, K. (1997). Student motivation in middle school: The role of perceived pedagogical caring. *Journal of Educational Psychology, 89,* 411-419.

Wentzel, K. (2010). Students' relationships with teachers. In J. L. Meece, & J. S. Eccles (Eds.), *Handbook of research on schools, schooling, and human development* (pp. 75-91). New York, NY: Routledge.

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.

Williams, T. T. (2008). *When women were birds: Fifty-four variations on voice.* New York, NY: Farrar, Straus, and Giroux.

Woollard, J. (2012, September). *Foetal Alcohol Spectrum Disorder: The invisible disability.* Report No. 15 for the Education and Health Standing Committee of the Western Australia Legislative Assembly. Perth, Australia: Parliament of Western Australia.

Wozniak, J. R. (2014, April). *Everything in moderation does not apply to drinking alcohol while pregnant.* Retrieved May 17, 2015 from http://www.mofas.org/2014/04/everything-moderation-apply-drinking-alcohol-pregnant/

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Appendix A

UNIVERSITY OF ALBERTA

FASD Specialists Letter of Introduction

"Evaluation of Alberta FASD Planning and Service Delivery"

Dear FASD Specialists:

You are being invited to participate in a study entitled **Evaluation of the Alberta FASD Planning and Service Delivery** that is being conducted by Dr. Jacqueline Pei and Dr. Cheryl Poth. This project begins February 2012 and concludes August 2012. With your participation, you will help us to gain a better understanding of the current model of collaborative practice and the existing links between research and the process of FASD planning and service delivery. This information will allow us to contribute to evidence-based practice to best meet the needs of FASD-diagnosed individuals.

You are being asked to participate in a focus group with 6-8 other FASD specialist participants to share your personal experience as policy makers, program coordinators, and service providers related to FASD policies, program planning and delivery of services. The focus group will take place at a mutually convenient location and time and it is expected to last about 60-90 minutes. After the focus group, we will share a summary of the collected information with you. Opportunity for further disclosure on an individual basis will also be provided. Also, if you are interested but cannot attend the focus group, an individual interview may be arranged.

Participation in this study is voluntary. No one will know whether they were selected or chose to participate in the project, or were not selected or chose not to participate. Participants may withdraw from the project at any time, without penalty, simply by notifying the researchers. Any information collected during the focus group and/or interviews will be kept confidential. Only the researchers will have access to this information and the analyzed data, to protect the rights, dignity, and welfare of all those who have agreed to participate.

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

If you should have any concerns at any time about the project you are urged to contact us. Contact information is listed below. If you know of a FASD specialist who may be interested in participating simply forward their names to the project coordinators: **Jenelle Job (jenellemjob@gmail.com) or Laura Gould (ldg@ualberta.ca).** Please keep this description of our work together for your records. Thank you in advance for supporting the evaluation of Alberta FASD planning and service delivery.

Sincerely,

Dr. Cheryl Poth
Ph: (780) 492 -1144
cpoth@ualberta.ca

Dr. Jacqueline Pei, R.Psych.
Ph: (780) 248-1167
jacqueline.pei@ualberta.ca

Appendix B

UNIVERSITY OF ALBERTA

Consent Form

"Evaluation of Alberta FASD Planning and Service Delivery"

- I have read and retained a copy of the letter of information concerning the study "Evaluation of Alberta FASD Planning and Service Delivery" and agree to participate in the study. All questions have been explained to my satisfaction. I am aware of the purpose and procedures of this study.

- I understand that my participation will involve one focus group or interview 60 to 90 minutes in length, with the possibility of a follow-up interview, with overall length of participation being a maximum of two hours. I have been informed that the focus groups and/or interviews will be digitally recorded. I understand that I will have the opportunity to review the summary and make additions and deletions.

- I have been notified that participation is voluntary and that I may withdraw at any point during the study without any consequences to the study. I understand that all measures to protect confidentiality will be taken in the focus group itself and with appropriate storage, access of data, and the use of pseudonyms.

- I understand that, upon request, I may have a full description of the results of the study after its completion. I understand that the researchers intend to publish the findings of this study or present them at a conference.

If I have any questions about this project, I am aware that I can contact the researchers, **Cheryl Poth at 780 492-1144 or cpoth@ualberta.ca** and **Jacqueline Pei at 780-248-1167 or jacqueline.pei@ualberta.ca**.

I understand that the plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

I HAVE READ AND UNDERSTOOD THIS CONSENT FORM AND I AGREE TO PARTICIPATE IN THE STUDY.

Participant's Name: ____________________________________

Signature: ____

Date: ____

☐ I am willing to be contacted for a follow-up interview or clarification of focus group comments.

If you wish to receive a copy of the results of this study, please write your email or postal address below.

Address: ____

Appendix C

Focus Group: Parent & Child Assistance Program

FACILITATOR'S GUIDE

Facilitator's Role

The facilitator's role is to moderate the discussion, to keep the conversation on track, to help participants to talk with one another, rather than engaging in question and answer, and to ensure that all topics are covered in the available time.

Each key question has been written as a probe to spark discussion. **Some key questions have two or three questions within them. Read the whole of each key question then repeat the first part if there are two or more parts. The second and third parts may be repeated or used as a probe**.

Try to obtain as many different points of view as possible on each topic. And try to foster interaction that explores participants' reactions in some depth.

Direct discussion toward concrete and specific accounts of participants' experiences so that the conversations elaborate on the detail and are not too general.

FACILITATOR'S INTRODUCTORY SCRIPT—READ OR "AD LIB" THE IDEAS.

Opening

[Facilitator introduces self and recorder.]

Thank you for joining us again for follow-up discussion around the issues that were brought up at the PCAP focus group in March.

We have reviewed the transcripts and have a few additional questions that we'd like to explore. Before we get underway, I just want to remind you of the ground rules for our focus group conversation:

- Only one person speaks at a time.
- No side conversations—these obscure the taping and interrupt the speaker.
- It is important that we hear from each of you, and that no one dominates the time.
- Either you or I will steer the discussion to another topic if conversation becomes unproductive.
- The recorder will note who is speaking, but will not participate in the discussion.
- There are ***8 main or key questions***, so we will allow approximately 10 minutes for each question.
- Just a quick reminder about confidentiality. In order to maintain the privacy of participants, please speak in general terms about colleagues including avoiding to refer to any colleagues by name, instead just refer to them as "my colleague." In addition, the discussion from this focus group interview is considered confidential among the participants.

Transition

Let's begin by asking each of you to introduce yourself by explaining your role in working with FASD.

We want to learn from you and from your experiences of collaboration and use of research in FASD related planning and/or delivering of programs and services. So, please think back to the experiences of being involved in these processes.

We're here to listen. If we go off track, we'll get you back on track—not that it isn't important but that we have a number of key questions to get through. We can talk further at the end if needed.

1. **Tell us your story about how the PCAP program changed over the past 5 years?**
    a. What are some key events that stand out for you?

2. **From your perspective, what might be the key strengths of PCAP programming and service delivery?**
    a. How do you know?

3. **From your perspective, what might be the key challenges of PCAP programming and service delivery?**
    a. How do you know?

4. **In what ways could the delivery of FASD programs and services be more effective?**
    a. What would you need to make this happen?

5. **Tell us about your training.**
    a. How has this training supported your work?
    b. If you wanted more access to information, how have you gone about this?

6. **In what ways has research and best practice informed your FASD strategic planning?**
    a. FASD prevention activities?
    b. FASD intervention activities?

7. **What role does the CMC play in your work?**
    a. What have your experiences collaborating with the CMC been like?
    b. How could the CMC be more effective in supporting your work?
    c. Have the efforts of the CMC increased availability to FASD research and best practices?

8. **Is there anything else you would like to add to our conversation today?**

SUMMARY OF KEY POINTS BY RECORDER

1. What would help you to carry out your work more effectively?

2. What might be some areas for future research?

Facilitator's Closing Script

Our time is over, so I must ask that we end this conversation. Thank you for participating.

Keep in mind…

- **Outcome 5: The planning and delivery of provincial government programs and services associated with FASD is accomplished through a collaborative approach.**

- **Outcome 6: Basic and applied research findings, including those from monitoring and evaluation systems, are used to inform FASD strategic planning, FASD prevention activities and FASD related programming.**

Appendix D

FACILITATOR CHEAT SHEAT

Emphasis: Tap into the participants' passion for FASD programming and service delivery

Helpful hints:

Make everyone feel welcome. ***Building rapport is key*** to achieving candid and honest responses!

Speak in a loud, clear voice & encourage participants to do the same.

After introductions, ***remind participants about confidentiality***. Use "my colleague" instead of a person's name.

Allow ***only one speaker at a time.***

Ask ***only one question at a time***. Allow time for responses then ***use probes*** for additional feedback and information. Probe for clarity if needed.

Be flexible in format. It is fine to go out of order in questioning. The goal is to answer all the questions in conversation rather than in a set order.

Include everyone in the discussion. Encourage quieter group members to contribute.

Vocalize body language for the recorder (e.g., head shaking in agreement or disagreement, pointing at other participants, facial expressions).

> → For example, if one person is speaking and three people are nodding say, *"I see that three of you are in agreement with what Participant 1 is saying."*

Keep the group on task and get through all the questions without exceeding the time limit.

Remain objective, so the participants feel comfortable sharing their opinions. Try not to say, "Good," "I agree," or "That's interesting." Instead, thank the participant for their opinion before moving on.

Allow diverse opinions to emerge. Diversity in opinion is great; however, ensure that emotions do not take over the conversation.

Talk as little as possible to allow participants ample opportunity to speak. However, you may have to direct the conversation at times to ensure you are staying on track and that the questions are being answered.

Avoid letting one person dominate the discussion. If necessary, ask different people to begin the discussion for each question.

Ensure you ***thank people*** for their participation at the end of the session!

Appendix E

Alberta FASD Parent & Child Assistance Program

Summary of Focus Group Sessions

Fetal alcohol spectrum disorder (FASD) is increasingly recognized as a significant social and health issue facing Albertans. Basic scientific research and other building blocks for effective FASD supports are now in the beginning stages, and programs and services for individuals with FASD are in their infancy in terms of both development and scope. To provide a coordinated approach for meeting the needs of individuals with FASD, the Government of Alberta established the FASD Cross-Ministry Committee (CMC). The formation of this committee resulted in the creation of the *FASD 10-Year Strategic Plan*.

Research efforts to evaluate FASD policies, programming, and service delivery across Alberta are an important component of this strategic plan. This research is being conducted through focus groups and interviews with FASD specialists (i.e. policy makers, program coordinators, and service providers). Specifically, our research objectives are: (a) to document the experiences of key stakeholders in the planning and delivery of FASD programs, with a focus on collaboration (b) to generate shared understandings related to best practices in FASD planning and service delivery, and (c) to detail the extent to which FASD program monitoring, research, and evaluation have informed planning, activities, and programming in Alberta.

A total of 21 individuals from PCAP across Alberta participated in 7 focus groups. These groups consisted of network chairs and coordinators, program managers, administrative personnel, and leadership team members. Due to the large numbers of focus groups, this summary will not be able captured everyone's perspectives, but it will reflect some common theme among the groups.

Participants began by discussing the change in PCAP program in the past five years. In particular, the common theme emerged across focus groups is a substantial program growth, including an increasing number of services and staff in Alberta. Along with the program growth, majority of the participants noticed that there is an increase of training opportunities (i.e. webinars and local PCAP training) and use of research (i.e. conferences and online database). As one participant explained:

"…within the program itself I think again the biggest change is working with that expediential growth. I've been with it for two years and we've gone from four clients to fifty two …"

Participants were then asked to identify the strengths and challenges of the PCAP program. Most participants described the strengths of the PCAP program including relationship building with clients, non-judgmental model, flexibility, strength-based support, and care and passion of the PCAP mentors. As one participant expressed the importance of relationship building with clients and PCAP mentor's care and passion:

"… programs and strategies don't heal people, relationships do and that' s just so important…it's not the programs that are great programs, it's the individuals who are doing it, because you can get somebody in the PCAP program and they can cause so much damage…"

For the challenges of the program, lack of funding was noted repeated across focus groups. Specifically, participants noticed that the issue of funding was seen as impactful to the delivery of the PCAP services (e.g., long waiting list and high staff turn-over rate), the resources available for their clients (e.g., lack of housing support), the awareness of FASD in the community, and the collaboration with other agencies. In addition to these external factors, most PCAP mentors felt that they did not have enough support (e.g., wages, overtime, transportation support, and worker safety issues), which in turn leaded to lack of self-care and compassion fatigue. As one participant elaborated that:

"... the challenges are in direct correlation with the strengths…so the fact that we're relationship based means it's intensive work and we're involved with these women for a long period of time so we're trying to keep a professional boundary at the same time really genuinely caring about them and connecting with them and having them feel that you care about them so that that's a challenge and along with that comes a lot of the trauma to the workers."

Despite the substantial challenges, participants identified ways so that service delivery could be more effective. A common theme was collaboration with other agencies to increase awareness and understanding in the community. Another theme emerged was having more resources from the government to better support clients and PCAP mentors. This point was articulated by one participant who expressed:

"we [PCAP programs] need to partner with education, with health and it shouldn't be up to us to present to them, it should be this is what's happening in your area, this is what's you know we're all working together and it should come down from the government not that we need extra direction but we should you know I don't think it should be up to us to always network and partner because it's hard enough to get services up and running let alone partner with huge sources of, never saying that we're taking care of that or that's something that we're not interested in right now, so again I can see that even from before as a worker I felt you know I had to explain my role in what I was doing and the importance of the role"

Another discussion theme was centered on participants' training. Most participants identified that PCAP program has a strong evidence-based foundation, which enhances the mentors' knowledge and supports their practices; however, most participants felt that ongoing and local training was needed. Despite the importance of training identified, participants described that there was lack of opportunities to receive PCAP training due to the mentor's busy schedule and insufficient funding allocated to training. As evidenced by one participant:

"I found it very valuable to take the training myself to get a better understanding of what the frontline workers are being expected to accomplish on the day-to-day basis and again getting back to the strength of the program and understanding where it's come from and the research that it's based on as well as the purposes of it and the mandate and the philosophies behind it and how it all roles together so nicely and understanding why the three years and what the focus of relationships look like and so we found that to be very beneficial and would like to see that continue as well…"

Next, participants discussed about the availability of FASD research and best practices and how this has informed strategic planning and service delivery. Three primary means that the participants obtain research are internet search, conferences, and webinars provided by CMC.

Furthermore, some participants expressed that most of the current research is theoretical driven, and they hoped to see more practical research in the future, so that they can incorporate more research into them practice. A participant explained: *"the training needs to come more from a practical base rather than a research base because research is really good down the road for outcomes."*

Participants, in general, noted that they did not have direct connection with CMC; thus they were not familiar with CMC; however, some of them were able to describe that CMC was related to funding, training, and research. One participant underlined this by stating:

" …what the CMC has provided that has been helpful of course has been the FASD conferences, the online Learning Series is excellent, it's great when you've got new staff and you can say okay even existing staff too to get more information, the research part uh has been awesome."

In summary, participants described three major changes in the PCAP program over the past five years: tremendous growth of the program, increase of training opportunities, and increase of research usage. On the topic of strengths, participants identified the key themes as relationship building with clients, non-judgmental model, flexibility, strength-based support, and care and passion of the PCAP mentors. Alongside with the strengths, most participants noted that the key challenges are direct correlated with the key strengths. Some key challenges that identified by the participants are lack of funding, the resources available for their clients, the awareness of FASD in the community, the collaboration with other agencies, and lack of support for the mentors, which has impacted the delivery of the PCAP services,. In term of training and research, most participants felt that the evidence-based PCAP program served as fundamental building blocks for their services; however, the participants felt that they needed more ongoing training and more opportunities to access research. Lastly, most participants did not have direct interaction CMC members, but they acknowledged that CMC tried to increase the training and research opportunities for mentors.

In term of the impact of the focus group, most research assistants found the sharing in the focus group was extremely moving for them. During the process of the focus groups, most research assistants felt a sense of frustration among the participants due to lack of support and undervalued by the government and community. Despite noticing participants' frustrations about the system support, the research assistants felt that participants had a strong passion, dedication and commitment to the clients, and strong team support among the mentors propelling the participants' ongoing support to the clients. As evidenced by one research assistant:

"I think the main thing for me was just seeing how passionate these people are about working with these at-risk mothers. In our group they even became emotional telling their stories. I know people are quick to judge mothers, and look down upon them for putting themselves and their children at risk by drinking, but hearing the stories these front-line workers told about some of the contexts behind their situations was a real eye-opener….it was a great experience to hear the other side of the story, since in our research we are usually focused on the child, their deficits, and interventions they need, etc. This focus on prevention and the struggles that are involved in working with this population definitely added to my understanding."

Appendix F

UNIVERSITY OF ALBERTA

Caregiver Letter of Introduction

"Enhancing the assessment process and implications for FASD-diagnosed students: Documenting the perspectives of classroom teachers, allied professionals, caregivers, and administrators."

Dear Caregiver:

This letter introduces **Enhancing the assessment process and implications for FASD-diagnosed students: Documenting the perspectives of classroom teachers, allied professionals, caregivers, and administrators** project. This project begins February 2009 and concludes January 2010.

This project documents the experiences of the individual classroom teachers, allied professionals, caregivers, and administrators related to FASD-diagnosed students. This project is an important step in increasing links between research and practice in the communication of assessment results and will allow us to contribute to evidence-based practice to meet the needs of FASD-diagnosed students, their classmates, and their teacher. If you or another caregiver is interested in participating you will be provided with the opportunity to share your experiences with fellow caregivers.

The project includes participation in one focus group with 6-8 other caregiver participants. The focus group will take place at a mutually convenient location and time and it is expected to last about 90 minutes. After the focus group a summary of the collected information will be shared for additions or deletions. Moreover, opportunity for further disclosure on an individual basis through phone or in person will be provided.

Individual participation is voluntary. No one will know whether you were selected or chose to participate in the project, or were not selected or chose not to participate. You may withdrawal from the project at any time, without penalty, simply by notifying the researchers. Any information collected during the focus group will be kept confidential. Only the researchers will have access to this information and the analyzed data, to protect the rights, dignity, and welfare of all those who have agreed to participate. If you should have any concerns at any time about the project you are urged to contact us using the information listed below.

If you or another caregiver is interested in participating, simply forward a name(s) to **Jenelle Job, project coordinator, at job@ualberta.ca** and she will answer any questions. Please keep this description of our work together for your records. Thank you in advance for supporting the development of FASD-related best practices.

Sincerely,

Dr. Cheryl Poth	Dr. Jacqueline Pei, R.Psych.
Ph: (780) 492 -1144	Ph: (780) 248-1167
cpoth@ualberta.ca	jacqueline.pei@ualberta.ca

Appendix G

UNIVERSITY OF ALBERTA

Consent Form

"Enhancing the assessment process and implications for FASD-diagnosed students: Documenting the perspectives of classroom teachers, professionals, caregivers, and administrators"

- I have read and retained a copy of the letter of information concerning the study "Enhancing the assessment process and implications for FASD-diagnosed students: Documenting the perspectives of classroom teachers, professionals, caregivers, and administrators" and agree to participate in the study. All questions have been explained to my satisfaction. I am aware of the purpose and procedures of this study.

- I understand that my participation will involve one focus group up to 90 minutes long. I have been informed that the focus groups will be recorded by a digital recorder. I understand that I will have the opportunity to review the summary and make additions and deletions.

- I have been notified that participation is voluntary and that I may withdraw at any point during the study without any consequences to the study. I understand that all measures to protect confidentiality will be taken in the focus group itself and with appropriate storage, access of data, and the use of pseudonyms.

- I understand that, upon request, I may have a full description of the results of the study after its completion. I understand that the researchers intend to publish the findings of this study or present them at a conference.

I am aware that I can contact the researchers, **Cheryl Poth at 780 492-1144 or cpoth@ualberta.ca** and **Jacqueline Pei at 780-248-1167 or jacqueline.pei@ualberta.ca**, if I have any questions about this project.

I understand that the plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education, Extension and Augustana Research Ethics Board (EEA REB) at the University of Alberta. I am aware that for questions regarding participant rights and ethical conduct of research, I may contact the Chair of the EEA REB at (780) 492-3751.

- Please sign this copy of the consent form and return at the focus group meeting

I HAVE READ AND UNDERSTOOD THIS CONSENT FORM AND I AGREE TO PARTICIPATE IN THE STUDY.

Participant's Name: ______________________________

Signature: ______________________________

Date: ______________________________

Please write your email or postal address at the bottom of this sheet if you wish to receive a copy of the results of this study.

Appendix H

Allied Professional Focus Group

FACILITATOR'S GUIDE

Facilitator's Role

The facilitator's role is to moderate the discussion, to keep the conversation on track, to help participants to talk with one another, rather than engaging in question and answer, and to ensure that all topics are covered in the available time.

Each key question has been written as a probe to spark discussion. **Some key questions have two or three questions within them. Read the whole of each key question. Then repeat the first part if there are two or more parts. The second and third parts may be repeated or used as a probe**.

Try to obtain as many different points of view as possible on each topic. And try to foster interaction that explores participants' reactions in some depth.

Direct discussion toward concrete and specific accounts of participants' experiences so that the conversations elaborate on the detail and are not too general.

FACILITATOR'S INTRODUCTORY SCRIPT—READ, PLEASE OR "AD LIB" THE IDEAS

Opening

[Facilitator introduces self and note-taker.]

Please sign a consent form.

Our research is aimed to inform our understandings of how teachers work with FASD-diagnosed students.

Some of our research involves listening to people who have experience with working with FASD-diagnosed students in the classroom. In this case, we want to hear from people like yourself who have been involved in the assessment process.

Before we get underway, I just want to review with you the ground rules for our conversation:

- Only one person speaks at a time.
- No side conversations—these obscure the taping and interrupt the speaker.
- It is important that we hear from each of you, and that no one dominates the time.
- Either you or I will steer the discussion to another topic if conversation becomes unproductive.
- The note-taker will note who is speaking, but will not participate in the discussion.
- There are ***eight main or key questions***, so we will allow approximately 8 minutes for each question.

- Just a quick reminder about confidentiality. As you know from the information letters that your name will not be recorded in the write up. As well, in order to maintain the privacy of participants, please speak in general terms about colleagues including avoiding to refer to any students, principals, fellow colleagues by name, instead just refer to them as “my colleague” or “my student”. In addition, the discussion from this focus group interview is considered confidential among the participants.

Transition

Let’s begin by asking each of you to introduce yourself by your first name and the grade in which you teach.

We want to learn from you and from your experience with the students. So please think back to the experiences of being involved with the students.

Key questions

1. **Think back to a time when you successfully implemented a strategy with a FASD-diagnosed student.**
   a. Describe the events that preceded
   b. Describe the event itself
   c. Describe what happened next for you and the student

2. **Think about a time when you experienced challenges working within the classroom with a FASD-diagnosed student.**
   a. Describe the events that preceded
   b. Describe the event itself
   c. Describe what happened next for you and the student

3. **What are three adjectives that describe what think about or how you feel when you are told you will have a FASD-diagnosed student in your class for the year?**

4. **What are your expectations of a FASD-diagnosed student in your class?**

5. **Think about your experiences with the assessment process that lead to a FASD diagnosis, what was your role?**
   a. As a recipient of the information
   b. As a communicator of the information

6. **What were the consequences of the diagnosis for the student?**
   a. positive aspects?
   b. negative aspects?

7. **What issues are the most pressing for a teacher working with a FASD-diagnosed student?**

8. **If you had a magic wand (anything was possible) what would enhance your ability to work with a FASD-diagnosed student in the classroom? Dream big!**

SUMMARY OF KEY POINTS BY RECORDER

Facilitator's Closing Script

Our time is over, so I must ask that we end this conversation. Thank you for participating.

Appendix I

Sample Summary for an Allied Professional Focus Group

In addition to teachers, administrators, and caregivers, there are many other professionals who contribute to the lives of children with FASD including but not limited to educational assistants, school counsellors, psychologists, speech therapists, and government caseworkers. To better understand the perspective of one particular group of allied professionals—***educational assistants (EA)***—with respect to the classroom experiences, assessment, and school-family relationships of children with FASD, a focus group was held with EAs from a congregated junior and senior high school site for children with cognitive, physical, and emotional/behavioural limitations. Success-oriented programs prepare students to be contributing members of society through a focus on literacy, numeracy, and employability skills.

Five EAs participated in the discussion (4 female, 1 male). The participants discussed a variety of topics including effective classroom strategies, student expectations, building relationships with students, parent-school relationships, assessment and diagnosis, and professional development.

The participants began by discussing various strategies used to teach students appropriate decision-making and limit misbehaviour. A strategy outlined by one EA relates to the anticipation of opportunities for student decision-making and to talk to him/her about possible actions to take and which choices would be the best:

> *"…a lot of times they'll still make just a bad a choice anyhow but at least then I can say, "Do you remember when we talked about this possibility?" "Yeah." "And remember we talked about the choices?" "Yeah." "Well, what did we think was going to work out?" "Well, that one…" "Well, let's go with that one." So, I try to sort of try to set the stage ahead of time so that I have something to draw back [on]."*

It was agreed that one of the most important things is building a relationship with the students through commonalities, humour, and the acknowledgement of positive qualities and/or skills. This helps students to be more open, focus on what is being said, and willing to accept feedback.

> *"I think that you would find something that interests that child,…I would find something that interests them and teach them that way. So if dinosaurs…are what [they like] then we'll learn everything through dinosaurs. Dinosaur cubes, stickers, whatever work…you customize your learning plans for their needs."*

The EAs noted that just as strategies differ from one student to the next so do expectations and it is important to adapt these based on individual capabilities and daily functioning. With students that are more capable, expectations are high and teachers and EAs will "push" accordingly. With other students, school personnel may expect to see very little but *"you plant some seeds in the hopes that somewhere down along the line they go "…maybe that [Mr. X] wasn't such an idiot after all 'cause this kind of makes some sense."*

> *"…it really depends on the kid. If the kid's capable then we push [him]…to achieve…I really try to be what the kid needs and I don't mean that I try to be their best friend…I can be their worst nightmare and a school bud depending on what the situation*

> *requires…it's trying to see what's going on, what are the motivations behind what he's up to and then trying to provide him what he needs…"*

The goal is to *"help [student] become contributing citizens"* and this requires modifying strategies and expectations to *"figure out what method works best for [each] student."* Although these methods are sometimes not supported by caregivers, the EAs reported that more often than not they have good communication with their students' families:

> *"…we do speak a lot to social workers, foster parents, guardians, aunts, uncles, grandparents, and some parents…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 to get them out there and support them while going out on work…So, it just depends on the family."*

> *"I love having access to the parents because I can model for them. They can see their child being successful. Instead of the child always being a problem except when they're bribing him with McDonald's or whatever…they can see the child being successful in some other things…they can start to see, "My child is not stupid. My child can do some things."…it's not necessarily always easy working with parents, but it can be really rewarding."*

With respect to their experiences with the assessment process, the participants reported frustrations with a lack of accessible information. The participants agreed that the students' CUM files are large, disordered, and often contain information that is negative, which could lead a teacher or EA to judge a student before getting to know him/her. Due to time and student numbers, the EAs stated that it just isn't feasible for school personnel to read through each student's file.

Instead, they suggested that it would be great to have a condensed version with information specific to the child's functioning and learning (e.g., medical problems, family background, *"major triggers,"* safety concerns, emotional and behavioural issues, and learning challenges) as well as effective strategies and possibly *"contact people…to maybe contact if you're in a sticky situation and you want to know how to deal with this situation with that child."*

> *"…even if you had at the start of the year if teachers get a class list with the name, a picture and what they're IQ [is]…[where] they're functioning at and…a few things about them. It doesn't have to have the whole CUM attached to it but just a little bit of something so that you know what you're getting and what to expect…and positive things, too. It doesn't have to be…huge. The teachers don't have time and we don't have time to be sitting there looking through a ton of information."*

Once a diagnosis is obtained, the participants and interviewer discussed some of the consequences for the student, which were largely seen as positive. One of the best parts of diagnosis and attending the present school is to be surrounded by like peers and develop friendships. Additional positives are the variety of disabilities, students helping each other, unique classes, the work experience program, and opportunities to be involved in numerous activities:

> *"I think I think our students get more here than any other school because we have so much more to offer them. We have a lot more staff, a lot more time that we can spend one-on-one with the students. We have a lot more classes like Animal Science and Sewing and…Mechanics…I think our school's amazing and it offers way more than a lot of other schools do. There's a lot more money coming into this school and a lot more opportunity for our students to grow."*

> *"Most other schools that these students would be integrated into never get an opportunity to try any of the vocational classes let alone…be full time."*

Finally, if given a magic wand to improve a teacher's ability to work with students with FASD in the classroom, the participants agreed that *"a condensed version of the CUMs"* with *"usable information"* would be particularly helpful. As well, one EA mentioned the need for transition support for students who have worked with a certain teacher and EA and then move to another classroom or school with a whole new teaching staff. Another participant noted the need for more professional development in an effort to stay current with strategies and best practices as well as learn the different presentations of disorders and how students with the same disability can be quite unique in their functioning:

> *"I personally think that if we had strategies for the disabilities that we do have, including FAS, and also if we were kept current on…educating ourselves, having on our PD days, having workshops and learning new things about new disorders so that we actually know…that would be [very] positive."*