

First Peoples Child & Family Review

An Interdisciplinary Journal

*Honoring the Voices, Perspectives and Knowledges
of First Peoples through Research, Critical
Analyses, Stories, Standpoints and Media Reviews*

2013
volume 8
number 1



First Nations Child & Family
Caring Society of Canada

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Foreword

Dorothy Badry,¹ Tara Hanson,² Jennifer King,³ Andrea Auger³

¹ Faculty of Social Work, University of Calgary, Calgary, Alberta, Canada

² Director of Knowledge and Partnership Development; Alberta Centre for Child, Family, and Community Research, Edmonton, Alberta, Canada

³ First Nations Child and Family Caring Society of Canada; Ottawa, Ontario, Canada

This special issue of *The First Peoples Child & Family Review* on Fetal Alcohol Spectrum Disorder (FASD) was published in partnership between The First Nations Child and Family Caring Society and The Alberta Centre for Child, Family and Community Research (The Centre).

The Centre was established in 2003 with a priority to support research on the prevention of Fetal Alcohol Syndrome and to build knowledge on how to improve outcomes for those affected by FASD. The Centre began funding studies, building and mobilizing knowledge about FASD after two commissioned State of the Evidence Reviews revealed critical gaps in the number of prevention and intervention programs being developed, implemented and evaluated.

Dr. Dorothy Badry, guest editor of this edition completed an International Research and Practice Inventory Review for The Centre in 2003. Over the years, Dr. Badry has and continues to make significant contributions to expanding our FASD knowledge base. Her recent work in the Northwest Territories with women in four northern communities is featured in the article “Brightening Our Homes Fires: An Exploratory FASD Prevention Project”.

Finally, this special edition was published as a sister issue to Volume 19(2) of the *Journal on Developmental Disabilities* (JoDD). We would like to acknowledge the JoDD for contributing abstracts to this issue. We invite readers to explore their upcoming issue for further reading on FASD.

The editorial board of the *First Peoples Child & Family Review*, in partnership with The Centre, would like to thank the authors in this edition for their important contributions to FASD knowledge and research. We would also like extend a heartfelt thank you to the youth, women, parents and community members who participated in this work by sharing their stories, knowledge and insights. We are honoured by your generosity.



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Caring Society of Canada**



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Editorial

Dorothy Badry,¹ Tara Hanson²

¹ Faculty of Social Work, University of Calgary, Calgary, Alberta, Canada

² Director of Knowledge and Partnership Development; Alberta Centre for Child, Family, and Community Research, Edmonton, Alberta, Canada

This special edition of *The First Peoples Child & Family Review* explores the social issue of Fetal Alcohol Spectrum Disorder (FASD) from the perspectives, experiences and needs of Aboriginal peoples. It recognizes that the context of FASD in Aboriginal communities is unique, and cannot be properly acknowledged or addressed through generalized studies and services. As the articles in this edition illustrate, the issue and experience of Aboriginal peoples and FASD must be understood within the context of colonization and its intergenerational impacts. Without this critical lens, research findings and service recommendations may be inappropriate to Aboriginal families or communities. Mainstream programs developed from a Euro-Western perspective may conflict with Aboriginal worldviews. The articles in this edition portray the human experience of struggles with alcohol, the role of history and trauma in adverse life outcomes as well as the existence of socioeconomic disparities. Experiences with child welfare and legal systems are chronicled, disruptions, difficulties and repercussive impacts of secondary disabilities. Along with the adversities, however, are powerful themes of hope, healing, promising practices, capabilities, and strength found through caring relationships.

The edition begins with a contextual overview. Steven Koptie refers to alcohol as “the great destroyer”, identifying the historical legacy of alcohol and the challenges faced by men, women and children living with FASD. He emphasizes the power of Indigenous Nations to stop the damage and revitalize the “good minds” of people into the future. Christine Werk, Xinjie Cui and Suzanne Tough examine FASD prevalence for children under the age of six living off reserve from the 2006 Aboriginal Children Survey. They identify the concern that one in four children in care have a diagnosis of FASD, and indicate that adverse life experiences and poverty are critical factors in FASD outcomes. Andrew Wilson, in a historical review of FASD highlights its’ positioning within a medical paradigm, and highlights the need for a shift to a social justice paradigm that is culturally sensitive. He further identifies the need for education on FASD to be embedded in social work curriculum and for human service workers be trained in intervention.

The issue then turns to explore specific issues and concerns faced by Aboriginal children, youth and families living with FASD. Authors explore topics related to the child welfare and justice systems, parenting and gender. Linda Burnside and Don Fuchs, presents the voices of 20 youth rarely heard, who face “dual challenges of being in child welfare care and coping with their disability”. Transition planning for youth “bound by the clock” is a particular struggle because of the developmental dismaturity and neurobehavioral problems experienced by youth, who continue to need support into adulthood and over their lifespan. The need to support placement stability and maintaining strong relationships with caregivers were identified as important foundations for youth in care with FASD.

Billy Joe Rogers, Kaitlyn McLachan and Ronald Roesch present research results suggesting that the inclusion of cultural and spiritual supports in the justice system hold value in promoting resilience and positive outcomes and for youth with FASD. The importance of the relationships between youth and caregivers are identified as a critical resource, as these relationships can positively impact psychological wellbeing and influence a decrease in offending behaviors for youth.

Peter Choate offers a critical examination of the role of Parenting Capacity Assessments for parents who themselves have FASD, and challenges the dominant perception that individuals with disabilities are not capable of parenting. The critical point is that FASD is not generally well understood as a spectrum disorder with a range of capacities. Tasnim Nathoo and colleagues profile four programs for pregnant and early parenting women who use alcohol and substances. These programs operate from an Indigenous knowledge framework, appreciating that FASD is a complex health problem and intervention strategies must consider harm reduction, cultural safety, violence and offering trauma informed care.

Deborah Rutman offers insight to promising practices and highlights the voices of 13 women living with FASD, sharing the results of a qualitative research project that included the voices of women participants, both Aboriginal and non-Aboriginal. Rutman presents a wholistic, wheel-based framework that situates women’s experiences in the context of their lives and looks positively at ‘what works’ for women. Erin Atkinson and colleagues describe the process of creating a quilt through research involving the Parent Child Assistance Program (PCAP), a home visitation program for women with a history of alcohol and drug abuse. The authors explore how the experience impacted both the participants and the researchers, and discuss how the study might inform future community-based research projects involving front-line workers in FASD prevention and support programs.

The final three articles take us to the Northwest Territories and profile the Brightening Our Home Fires Project that took place between 2010 -2012 using Photovoice, a form of participatory action research. This trio of articles begins with an examination of the literature on FASD and child welfare engagement and provides a model that considers three key factors: alcohol, trauma and child welfare as contributing to the challenges associated with responding to FASD. The second article highlights this exploratory research and the value of Photovoice as an approach to meaningful engagement and shares the photos of women who experience homelessness in Yellowknife. The third article, “Healing through Photography”, is a creative piece offered by community leader Annie Goose from Ulukhaktok, an Inuit community. The photos represented speak volumes about values such as community, family, tradition, culture and healing.

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Fetal Alcohol Spectrum Disorder among Aboriginal children under six years of age and living off reserve

Christine M. Werk,^{1,2} Xinjie Cui,^{1,2} and Suzanne Tough^{1,2,3}

¹ Alberta Centre for Child, Family, and Community Research, Canada

² School of Public Health, University of Alberta, Canada

³ Faculty of Medicine, University of Calgary, Canada

Corresponding author: Christine M. Werk, cwerk@research4children.com; 780-408-8767

Abstract

Fetal Alcohol Spectrum Disorders (FASD) are caused by consumption of alcohol during pregnancy and the prevalence of these disorders in Canada is not well established. Statistics Canada's Aboriginal Children's Survey (2006) was used in the current study to assess the prevalence of FASD among Aboriginal children living off reserve across Canada. Characteristics of Aboriginal children with or without a diagnosis of FASD and living in Western Canada were also assessed. Rates of FASD were higher in Alberta and Manitoba than other provinces and territories. For these children who were diagnosed with FASD half received treatment for FASD and treatment rates did not vary across provinces. In Western Canada, FASD was more common among children identified as First Nations, and among older children. Rates of FASD were also higher for Aboriginal children who lived in low income situations, who had experienced food insecurity, or who lived with foster parents. Therefore, Aboriginal children with FASD likely experience other life challenges and these factors should be considered when treating these young children.

Introduction

Fetal Alcohol Spectrum Disorders (FASD) are a group of serious and preventable conditions caused by maternal consumption of alcohol during pregnancy (Chudley et al., 2005; Elliot, Payne, & Bower, 2006). The consequences of alcohol consumption during pregnancy are a complex interplay between maternal physiology, nutritional status, alcohol dose and timing, and fetal susceptibility. The consequences of prenatal alcohol exposure include Fetal Alcohol Syndrome, Partial Fetal Alcohol Syndrome, Alcohol-Related Neurodevelopmental Disorder, and Alcohol-Related Birth Defect. Understanding more about FASD in Canada is important for both prevention and treatment efforts.

Alcohol use in adulthood has been associated with adverse events in childhood such as abuse (emotional, physical, or sexual), domestic abuse of the mother of the child, parental substance use, mental illness in the home, separation or divorce of parents, and incarceration of a family member (Dube, Anda, Felitti,

Edwards, & Croft, 2002). There is a cumulative effect such that the more adverse events or risk factors the more likely a mother is to use substances (Dube et al.; Nair, Schuler, Black, Kettinger, & Harrington, 2003). Aboriginal mothers have been shown to have a high risk of adverse life events that could be associated with substance use during pregnancy. For example, Aboriginal women are more likely than non-Aboriginal women to experience male partner violence (Brownridge, 2003), to be single parents, and to have larger families compared to non-Aboriginal women (Statistics Canada, 2012).

The prevalence of FASD has been estimated at 0.5 to 2.0 per 1000 live births (May & Gossage, 2001). Based on a synthesis of Canadian data, FASD has been shown to be higher in Aboriginal than non-Aboriginal populations in Canada (Tough & Jack, 2011). In studies of sub populations, including children in custody of children's service, those who encounter the justice system, and among Aboriginal children, rates of FASD ranging from 0.0087% to 23.3% have been found (Tough & Jack). These research findings are mostly from small communities though, and may not be representative of the general population in Canada (Chudley et al., 2005; May et al., 2008). More accurate and more representative prevalence data would assist in determining the influence of interventions designed to reduce FASD and for the design of prevention programs.

Fetal alcohol spectrum disorders require a multidisciplinary team of professionals for an accurate diagnosis (Chudley et al., 2005; Rasmussen, Horne, & Witol, 2006). Early diagnosis of FASD, especially in the preschool years, would provide the opportunity for early intervention (Streissguth, Barr, Kogan, & Bookstein, 1997) so that appropriate treatment can be implemented. Early diagnosis and treatment of FASD is important because children with a FASD diagnosis also typically experience mental health conditions such as attention deficit and hyperactivity disorder (Chudley et al.), cognitive challenges such as low intelligence (Burd, Klug, Martsof & Kerbeshian, 2003; Premji et al., 2004; Rasmussen et al.; Streissguth et al., 1994), and other secondary disabilities such as educational problems (Robinson, Conry, & Conry, 1987) and trouble with the law (Fast, Conry, & Loock, 1999; Popova, Lange, Bekmuradov, Mihic, & Rehm, 2011). Even though early treatment is important, low and variable service use has been observed among young children living with FASD (Mills, McLennan, & Caza, 2006).

Children with FASD often experience additional threats to their development as a consequence of low socioeconomic status (Bingol et al., 1987) and inconsistent parenting resulting from multiple foster care placements (Fuchs, Burnside, Marchenski, & Mudry, 2007). This suggests that children with FASD likely face additional life challenges throughout development and this may be particularly true for Aboriginal children.

The purpose of the current report was to provide insight into the prevalence and treatment of FASD among Aboriginal children under six years of age in Canada using the 2006 Aboriginal Children's Survey (ACS) conducted by Statistics Canada. The characteristics of children with FASD in Western Canada and the Territories were also assessed.

Method

The ACS is a post-censal survey of young Aboriginal children (aged 0 to 5) living off reserve in Canada in 2006. For more details on the ACS, consult Statistics Canada's concepts and methods guide (Statistics Canada, 2008). In 2006, there were approximately 135,000 Aboriginal children in Canada and 76,700

Aboriginal children in Western Canada and the Territories. A sample of these children's caregivers participated in the ACS and their responses were weighted to infer the entire population of young Aboriginal children living off reserve. While the research and analysis are based on data from Statistics Canada, the opinions expressed do not represent the views of Statistics Canada.

Two analyses were conducted using the ACS. First, FASD diagnosis and treatment prevalence as reported by parents was assessed for provinces when the sample size and estimate was large enough for ethical release from Statistics Canada. The goal of the second analysis was to determine characteristics of Aboriginal children living in Alberta but because the sample size was too small to assess Alberta alone, data from four western provinces (British Columbia, Alberta, Saskatchewan, and Manitoba) and the territories (Yukon, North West Territories, and Nunavut) was combined. This combination enhanced the stability of the estimates and enabled more detailed analysis, as the sample size is larger. The relevance to Alberta was preserved because many of the diagnostic approaches are similar across these jurisdictions (Clarren & Lutke, 2008). Cross tabulations of FASD were generated across age, gender, Aboriginal identity, urban/rural region, low income, food insecurity, and living arrangement.

The child's Aboriginal identity was reported by a parent or guardian. Aboriginal identity was grouped into three categories: First Nations, Métis, and Aboriginal ancestry. Children who were reported as having an Aboriginal ancestry but were not identified as First Nations or Métis were put into the "Aboriginal ancestry" group. A small proportion of children were identified as both First Nations and Métis; these children were counted in both categories. Low income was defined as families who spend 70% or greater of their before-tax income on basic household necessities (food, shelter, clothing) using the 2006 Census, and known as the Low Income Cut Off in Canada. The food insecurity measure was based on the child having ever experienced hunger due to lack of food. The living arrangement measure was categorized as children living with two parents (including at least one biological), a single parent, with two foster parents, or in alternative living arrangements with relatives or other guardians (Statistics Canada, 2008).

Analyses were conducted at a Statistics Canada Research Data Centre. SAS version 9.2 was used in combination with SAS-callable SUDAAN, version 10.0 for all statistical analyses. Estimations were computed using weighted estimates and variance was computed using ACS survey bootstrapping (1000 weights). Wald F^2 was used because cross tabulations were categorical and pair wise comparisons were assessed using 95% confidence intervals. The following standard Statistics Canada symbols were used to indicate caution with estimates:

E: The estimate must be used carefully as it is associated with a high level of error.

F: The estimate does not meet Statistics Canada's quality standards.

Results

Aboriginal children living in the Western provinces were significantly more likely to have had a diagnosis of FASD with rates in Alberta and Manitoba at 1.3%^E, compared to Canadian rates at 0.7% (Table 1). In British Columbia rates at 0.9%^E were not significantly different from the other Western provinces or Canadian rates. The other Canadian provinces and territories had FASD rates too small to be reliably reported from the ACS.

Table 1.

Percentage diagnosed with FASD by province, Canadian Aboriginal children aged 0 to 5

Canadian region	% diagnosed with FASD	95% confidence interval	Coefficient of variation	WALDF (χ^2)
Canada	0.7%	0.5- 0.8%	11.1	$\chi^2(7)= 7.35, p < .01$
Alberta	1.3%	0.9- 1.9%	19.5 ^E	
Manitoba	1.3%	0.8- 2.0%	23.1 ^E	
British Columbia	0.9%	0.6- 1.5%	24.4 ^E	

*Note: other provinces and territories had estimates too small to report

E: The estimate must be used carefully as it is associated with a high level of error.

Half of Aboriginal children living in Canada that had received a diagnosis of FASD had received treatment for FASD (50.0%). There was no difference in treatment rates between Alberta (59.3%) and British Columbia (50.0%; Table 2). Too few Aboriginal children were reported to have been diagnosed with FASD in the other provinces and territories to be able to compare treatment rates from these regions.

Table 2.

Percentage diagnosed with FASD who received treatment by province, Canadian Aboriginal children aged 0 to 5

Canadian region	% treated for FASD	95% confidence interval	Coefficient of variation	WALDF (χ^2)
Canada	50.0%	39.1- 61.1%	11.3	$\chi^2(14)= 1.39, p = 0.15$
Alberta	59.3%	42.0- 74.2%	14.3	
British Columbia	50.0%	21.4- 64.8%	29.5 ^E	

*Note: other provinces and territories had estimates too small to report

E: The estimate must be used carefully as it is associated with a high level of error.

F: The estimate does not meet Statistics Canada's quality standards.

The following analyses are based on Aboriginal children living in Western Canada and the Territories.

The reported prevalence of FASD among children living in Western Canada and the Territories with a First Nations identity was 1.7% compared to 0.7%^E among Métis children; there were not enough children with Aboriginal ancestry (but no Aboriginal identity) diagnosed with FASD to enable reporting within Western Canada and the Territories (Table 3). Children aged four to five years were more likely to be diagnosed with FASD than children under age two (1.6% versus 0.4%^E). There were no significant differences in diagnosed FASD by gender (Table 3).

The reported prevalence of FASD among Aboriginal children living in a low income situation was 1.5% compared to 0.7% of children not living in a low income situation (Table 3). Aboriginal children in Western Canada and the Territories who were reported to have experience food insecurity were more than twice as likely to have a diagnosis of FASD (2.7%) compared to Aboriginal children who had never experienced food insecurity (0.8%; Table 3). One in four Aboriginal children living with two foster parents (25.9%) was reported to have been diagnosed with FASD (Table 3). This was substantially higher than the proportion of Aboriginal children in Western Canada and the Territories diagnosed with FASD who were living in alternative arrangements with relatives or non-relatives (7.8%) or living with a single parent (0.7%^E; Table 3). The number of Aboriginal children diagnosed with FASD and living with two biological or adoptive parents was too small to report.

Table 3.

Percentage diagnosed with FASD by Aboriginal identity, age, gender, income status, and living arrangement, Aboriginal children aged 0 to 5 living in Western Canada and the Territories

Indicator	% diagnosed with FASD	95% confidence	Coefficient of variation	WALDF (χ^2)
Total	1.0%	0.8- 1.2%	12.3	
First Nations	1.7%	1.2- 2.2%	14.6	$\chi^2(2)= 17.47, p < .01$
Métis	0.7%	0.4- 1.0%	22.14 ^E	$\chi^2(2)= 4.43, p < .05$
Aboriginal ancestry	—	—	F	—
Age 0-1	0.4%	0.2- 0.7%	32.5 ^E	$\chi^2(4)= 5.16, p < .01$
Age 2-3	0.8%	0.5- 1.2%	20.6 ^E	
Age 4-5	1.6%	1.2- 2.1%	15.2	
Male	1.1%	0.8- 1.4%	14.7	$\chi^2(2)= 0.89, p = 0.41$
Female	0.9%	0.6- 1.2%	18.2 ^E	
Low income	1.5%	1.0- 2.1%	17.9 ^E	$\chi^2(6)= 4.37, p < .01$
Not low income	0.7%	0.5- 1.0%	16.9 ^E	
Food insecurity	2.7%	1.4- 4.9%	29.0 ^E	$\chi^2(4)= 3.71, p < .05$
No food insecurity	0.8%	0.6- 1.1%	6.5	
Foster parents	25.9%	18.9- 34.0%	15.0	$\chi^2(6)= 13.82, p < .01$
Alternative living arrangement	7.8%	4.2- 13.1%	29.1 ^E	
Single parent	0.7%	0.4- 1.2%	24.9 ^E	
2 parents (including one biological)	—	—	F	

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F: The estimate does not meet Statistics Canada's quality standards.

Discussion

The rates of diagnosis for FASD for Aboriginal children were higher for children living in Alberta and Manitoba compared to the rest of Canada. This finding could be a consequence of true rates of variability across Canada; however, over the last 10 years Alberta, Manitoba, British Columbia, and the Yukon have made significant investments in the development of diagnostic and assessment programs (Clarren & Lutke, 2008), which can lead to identification of more cases.

Approximately half of children diagnosed with FASD were reported to have received treatment for FASD. The low intervention rate for children with FASD is a key finding given the value of early treatment for children diagnosed with FASD for both optimizing current developmental function and for prevention of secondary disabilities (Chudley et al., 2005; Mills et al., 2006; Streissguth, et al., 1997).

In Western Canada and the Territories, older children were found to be more likely to have a diagnosis of FASD most likely because older children had more opportunities to be diagnosed. First Nations children had a higher rate of FASD than children identified as Métis. High rates of FASD have also been found on reserves in Canada in past studies (Robinson, et al., 1987; Square, 1997) however more recent prevalence rates are not available. The rates found among young Aboriginal children living off reserve in the current study were substantially lower than previous on reserve rates from those select communities (1.7% versus 10-19%; Robinson et al.; Square, 1997). Therefore, First Nations children living off reserve had higher rates of FASD (1.7%) than other Aboriginal children in this study (0.7%) but appear to have lower rates than past reports of First Nations children living on select reserves (10-19%).

Many Aboriginal people have elevated exposure to adverse life events such as domestic abuse (Brownridge, 2003), sexual abuse, economic instability (Statistics Canada, 2012), colonization and separation from family (residential school; Stout & Peters, 2011) and these kinds of adverse life events are associated with increased risk of substance abuse (Dube et al., 2002; Hillis et al., 2004). As a consequence of these exposures, First Nations mothers may be at higher risk of entering pregnancy with a substance abuse problem.

Children experiencing economic challenges such as living in low-income situations or experiencing food insecurity were also more likely to be diagnosed with FASD. This indicates that part of the support needed by children with FASD may include addressing basic needs such as access to food. In addition, the risk of alcohol-exposed pregnancies may be addressed in part by early identification of families at risk for adverse events (Tough, 2010) such as economic instability, past history of addiction or past interaction with child welfare. Aboriginal women may be particularly at risk for economic instability due to high rates of lone parent families and large family size (Statistics Canada, 2012).

One in four young Aboriginal children living with foster parents had received a diagnosis of FASD. Fuchs, Burnside, Marchenski, and Mundry (2005) found a similar proportion (17%) of children in Manitoba who were removed from their homes had been diagnosed with (or suspected of) FASD and the majority of children with FASD were Aboriginal. Researchers have previously found that addiction and severity of alcohol use is related to children being placed in foster care, and loss of guardianship is associated with a number of maternal experiences including: psychological distress, history of abuse, less prenatal care (Mills, et al., 2009) as well as economic instability and impaired judgment/emotional stability (Grella,

Hser, & Huang, 2006). Indeed, in a recent study by Douzgou and colleagues (2012) 74% of children who were seen for an assessment of FASD were either in care, or cared for by adoptive parents. Additional resources or services for FASD related challenges for foster parents may also be warranted to optimize outcomes for children with FASD.

Rates of FASD according to the national survey are in alignment with work reported by others; however, rates vary across regions in Canada. First Nations children were more likely than Métis children to have been diagnosed with FASD. Furthermore, rates of diagnosis were slightly higher among children living in low income situations or experiencing food insecurity, and much higher among children requiring foster care services indicating that foster parents of children with FASD may benefit from additional support, services, education or training. The reason for the variability in rates should be further evaluated to determine if differences reflect access to diagnostic services, mechanisms for referral, or true differences in the population.

Limitations

The present study was limited in that a non-Aboriginal comparison group was not available for contextual comparisons; the rate of FASD in the young non-Aboriginal population is not known. Diagnoses of FASD were reported by the children's caregivers and may have been over or under reported. In addition, the diagnostic criteria for FASD requires a multidisciplinary team and consequently, there may be under diagnosis (Nevin, Christopher, Nulman, Koren, & Einarson, 2002; Sokol, Delaney-Black, & Nordstron, 2003).

Acknowledgements

Assistance with data analysis by Irene Wong at Statistics Canada's Research Data Centre was greatly appreciated. We acknowledge that Alberta Human Services (formerly Alberta Children and Youth Services) and the Office of Statistics and Information (OSI) provided access to the Research Data Centre (University of Alberta) to analyze the data from the ACS.

Key messages

Professionals: Only half of young Aboriginal children diagnosed with FASD had received treatment. Interventions that are integrated, family focused, and culturally appropriate should be readily available for young children since early intervention can improve development and reduce the risk for life long problems.

Policy makers: The basic needs of young Aboriginal children with FASD may be unmet and addressing the underlying issues such as poverty, food security, social and parent support, and safe housing, may improve quality of life for children with FASD and reduce secondary disabilities, school failure, and involvement with justice system.

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An Interdisciplinary Journal

*Honoring the Voices, Perspectives and Knowledges
of First Peoples through Research, Critical Analyses,
Stories, Standpoints and Media Reviews*

Alcohol is a great destroyer: A call for insight on ceremonial approaches for coping with FASD

Steven Koptie¹

¹ M.Ed., Ontario Institute for Studies in Education, University of Toronto, Ontario, Canada

Corresponding author: Steven Koptie, koptie.steven@gmail.com

Abstract

As a seasoned community helper, I worry about the generation now assuming roles as healers, leaders and warriors, and continuing the fight for fundamental change in the relationship between Canada's Indigenous peoples and those privileged to inherit colonial legacies of European global colonization. I now view my personal journey of self discovery as an unending marathon. I honour "Runners" like Tom Longboat who represented the strength and vitality of healthy and sober communities. Traditional runners were as dependent on path-finders as we are today, yet they travelled with dedication and carried important information that sustained community integrity. Open discussion about the devastation of FASD is the most important conversation required across our territories today. We need to prepare good messages and good minds for the next generation to bring forward. This self-reflective paper seeks solace in rituals such as the Haudenasaunee Reqickening Addresses to allow those who suffer to "stand again in front of the people."

Introduction

"Now, moreover...it is...the calamity, so direful, that has stricken thy person...I shall speak such words that I will soothe and appease by [caressing] thy guardian spirit... The being that is demonic in itself...the Great Destroyer, that it is, that every day and every night roams about... [where] it exclaims[s] 'I, ...will destroy the Commonwealth [the League], ...now we have wiped the tears away from our faces...that customarily takes place when a distressful event has befallen a person, that the flesh [and] body...becomes obstructed.... Moreover, the

powers of life usually are lessened.... [When] it comes to pass where a direful thing befalls a person, that the Sun becomes lost to that person, customarily.... Now, I have set in order all thy affairs...it shall be possible that they shall again set his face fronting the people, that they shall again raise him up [requicken him], that they shall again name him, and that also he shall again stand in front of the people.” (Hewitt, 1985)

I have recently returned to community service work in youth mental health and once again have come face to face with the devastating impacts of prenatal exposure to alcohol, Fetal Alcohol Spectrum Disorder (FASD). The tragic life trajectories of prenataally exposed alcohol affected men, women and children cry out for a multi-generational recognition and mourning of colonial trauma. Alcohol was a currency in the fur trade and available at all negotiations, treaty or otherwise (Koptie 2009b), and continues to be a currency of dispossession and loss today. The Honourable Frank Iacobucci (2013) opened his Independent Review Report “First Nations Representation on Ontario Juries with the following dedication;

This report is dedicated to the men, women, and children of First Nations in Ontario whose perseverance and courage in the face of adversity and challenges continue to be an inspiration. (Iacobucci, 2013)

The Honourable Frank Iacobucci (2013) reported on consultations with Indigenous lawyers, scholars and community stakeholders’. One of these summaries stands out as a powerful reminder of the vast misunderstandings and impasses between Canadians and Indigenous peoples of the Canadian Dominion. Indigenous men, women and children living with FASD remain the most vulnerable to these chasms.

Summary 26 of that document calls to Indigenous scholars and writers, referencing cultural interference cloaked as “best practices,” “evidence-based,” and “the violence of benevolence” (Wesley-Esquimaux, 2011) by Canadian “helpers.” Wesley-Esquimaux (2011) calls the “violence of benevolence” the intentional institutionalized incapacitation of Indigenous peoples humanity. Wesley-Esquimaux (2011) calls for those have never considered Canada’s hybrid history legitimate, to “Get Out of the Way,” so the restoration and reclaiming of Indigenous Knowledge and Ways can flourish. The Honourable Frank Iacobucci reports;

(26) ...First Nations leaders and people spoke about the conflict that exists between First Nations’ cultural values, laws, and ideologies regarding traditional approaches to conflict resolution, and the value and laws that underpin the Canadian justice system. The objective of the traditional First Nations’ approach to justice is to re-attain harmony, balance, and healing with respect to a particular offence, rather than seeking retribution and punishment. First Nations people observe the Canadian justice system as devoid of any reflection of their core principles or values, and view it as a foreign system that has been imposed upon them without their consent (Iacobucci, 2013).

Indigenous peoples are challenged to engage in modern warfare against disadvantage, to end the legacy of vulnerability challenging our collective humanity through the spirit called “alcohol” (Duran and Duran, 1995). It remains a constant companion and a source of false solace in places where despair reigns. Will future generations learn from our stories of resistance, resentment and rebellion waged against colonial inertia, because we will have stood strong, and declared, “no more?” Will we wipe our tears, clear our throats and unplug our ears so we can escape the impact of alcohol damaged men, women and children across our lands? We can fight for everyone.

Eduardo Duran encourages a “Hybrid Approach” to deconstructing internalized oppression:

Hybrid is a term that has emerged out of postcolonial thinking and basically means there can be two or more ways of knowing and this can be a harmonious process. The concept of ideas existing without hierarchy is key to the liberation and healing process. Decolonizing is a process of liberation. In other words, we are going beyond colonizing, because colonizing is a dehumanizing activity. It is important to mention that I believe we must transcend the notion of “cross-cultural,” “cultural sensitivity,” and other such ideas that have been in vogue for some time in our fields. (Duran, 2006:14)

Although I have extensive social service training, a research background, as well as “on the ground” experience as a community worker, I wish to briefly put aside the wisdom I have accumulated over 30 years of community service, with great humility to address the true heroes of alcohol warfare, people living with FASD and their caregivers. I could reflect on numerous lessons learned, strategies attempted, and agonizing failures to mitigate the damage done by undiagnosed FASD amongst those I have had the privilege to work with, but I want to acknowledge what we have through the strengths of our Elders and traditional ceremonies.

As I search for kind and gentle service practices to emulate the great teachers who have guided as well as inspired my life work, I am inspired by the concept of “Wise Practices” for community re-development within Indigenous communities (Wesley-Esquimaux, Snowball 2011). This concept speaks to the remembering of “our own ways” when it comes to cultural integrity and the restoration of communal acknowledgement and care. Indigenous peoples have struggled as “warriors” in the war against colonization or as “runners,” collecting and delivering messages from good minds with good intentions to ensure the continuity of good will across our territories for generations. FASD in our families and communities remains an attack on the integrity of our future generations that we have the power to arrest.

In 2002, at Hamilton, Ontario in a workshop on FASD, Mohawk Elder Tom Porter posed a troubling question, “How many of these children can we care for?” Have we answered this query effectively as of yet?

I can confirm as a family therapist, working in a Toronto Youth Mental Health agency, that the life-long complications of FASD cross all racial, cultural, and class structures and goes far beyond impacting what society has come to regard as “Drunken Indians” (Koptie, 2009b). I trace my ancestry from the Six Nations Mohawk peoples. I, like so many of my peers, have struggled to reclaim the teachings of my ancestors, through the generosity and kindness of Elders, Story-tellers and Wisdom Keepers. This paper is framed to prompt Indigenous Research of Indigenous Knowledge, because we must awaken the utility and promise of ceremony. We must see ceremony as a powerful reminder of our responsibility to the vulnerable and yet unborn. It is in our power as Indigenous Nations to stop the damage and protect and revitalize the “good minds” of our peoples into the future.

In 2003, Caroline L. Tait authored, “Foetal Alcohol Syndrome Among Aboriginal People in Canada: Review and Analysis of Intergenerational Links to Residential Schools” for the Aboriginal Healing Foundation. Her text provided a valuable critique of FASD literature, and discussed the “limited range of variables, the focus on information that is mostly medical, behavioral, justice and educational in nature, and how limited attention is given to research on intergenerational and collective trauma (Tait, 2003: XVIII). She noted that Indigenous peoples in Canada are negatively represented in each of those spheres, with little contextual representation of the realities of colonial “best practices” such as residential schools and adversarial child welfare systems. Canada’s hidden history of “inferiorizing Indigenous communities” (Lee Maracle and Koptie, 2010) requires the kind of research attention that would expose the resulting colonial poverty generated by intentional design and neglect. This paper is an invitation to join in ceremonies or rituals of grief for the *intentional victims* and the destruction that alcohol has unleashed over the past seven generations among Indigenous Peoples globally.

In addition, Duran’s (2006) hybrid idea has not been taken into consideration when it comes to treatment, education and creating relevant avenues of support for families and caregivers impacted by FASD. There is no systemic accommodation for Indigenous knowledge or traditions to cope with the simplest to the increasingly extreme circumstances many communities face with increasingly prevalent rates of FASD in their midst (Tait, 2003). The disproportionately high rates of men, women and youth with FASD in the justice system has demonstrated connections to FASD secondary disabilities and the social markers of permanent brain structure damage related to prenatal alcohol exposure (Conroy and Fast, 2000). This discussion on FASD societal impacts is valid in many sectors of our society, not just disadvantaged Indigenous peoples. The conversation must be put front and centre so the affected can “stand in front of people” as reminders of our obligation to provide care and protection, and, to teach the truth.

In 2010, working in the Ontario public service in Aboriginal justice, I was instructed to not talk about FASD because the government did not want “everybody” to think FASD was just about Aboriginal people. This scourge is most certainly not “just about Aboriginal peoples.” It is an element of over-representation of all damaged Canadians from the violence of alcohol abuse, but especially of Indigenous men, women and youth in the justice system:

While [aboriginal] people comprise 2% of the total Canadian population, they represent 13% of the federal correctional institutional population. The rates may be higher for women and youth (Conroy and Fast, 2000: 51).

I was raised off reserve, on a travelling carnival, a dispossessed Indigenous man with no natural Indigenous Knowledge, struggling to revive what is retained in my blood memory. I trace my Indigenous ancestry through my Mohawk mother and like Fred Wheatley, at age 57, I can with painful humility say “I do not know enough about my traditional ways.” My greatest shame is not being able to recite the Thanksgiving Prayer in my mother’s language, Mohawk. Walking in two worlds can create perceptual, spiritual and cultural confusion. I also carry many observations and recollections of being a “carny bum” witnessing the dark experiences of so many men, women and youth who I now suspect were living with FASD. Allan Shows was a structured, controlled environment where “roustabouts”¹ could escape excessive expectations and for their families a 6 months respite. Who knew what eccentric behaviors were? Who cared if you were hiding from the justice system? The only worry was having enough weekly “stamps” for “EI,” Employment Insurance, income security for winters.

¹ Also known as carnival workers.

There were seasonal carnival workers who, in the fall, would turn themselves into the justice system to “serve their bit,” to serve their most recent sentences or commit small crimes to be incarcerated before winter. These miserable people (Les Miserable) escaped homelessness and hunger through incarceration. The residual impact of FASD on men, women and children warehoused in jails speaks loudly to fixation on colonial justice. Charles , Victor Hugo and Fyodor Dostoyevsky eloquently told stories of brutal injustices. Many Layers of Thank You to Lee Maracle, Thomas King, and Richard Wagamese for their eloquent story-telling to record our traumatic experiences.

I am drawn back to a moment as a young mental health worker, hearing the late Anishnawbe Elder Fred Wheatley declare, “I am 72 years old and I don’t know anything.” Fred Wheatley was responding to a Corrections Canada worker’s question, “Why don’t you Indians tell us anything?” Fred Wheatley’s gentle honesty as a survivor of multiple wounds from his life experience of fending off traumatic colonial attacks on his humanity remains a powerful life-guide for me. Fred Wheatley with great humility, courage and respect explained to people most familiar with “Drunken Indians” that Indigenous peoples are just beginning to understand the painful legacies carried forward by the trauma of residential schools, land dispossession, Treaty violations, and child welfare attacks on First Nations communities.

No scientific research has provided concise answers to “why Indians drink”. Yes, we know that alcohol has been the currency of colonialism in every euro-centric exchange. No government consultant on “best practices” will truthfully include the suffering of our ancestors as root causes to the social turmoil endemic to epidemic calamities such as FASD. It is current and next generations of Indigenous scholars that will hopefully close the gap of understanding by following the path of Indigenous philosophers, wisdom keepers and Indigenous Knowledge carriers, such as Ernest Benedict, Oren Lyons and Seneca scholar, John Mohawk who have long championed, “Thinking in Indian” (Barreiro, 2010).

Like many of my generations’ peers we watch, listen and learn how to reclaim our human right to know our traditional Indigenous ways. As our history is corrected and shared we are learning to be proud of the great sacrifices and contributions our ancestors made to Canada. Our past has always been to survive to fight another day (Koptie, 2009a). And yet, walking in two worlds can create perceptual, spiritual and cultural confusion.

As we recover our true identities and mourn traditional wisdom decimated by a massive collective dispossession story, I have learned to value life-long learning as a path to reconstituting the ideas of great faith-keepers like Dr. John Mohawk.

Reading Dr. John Mohawk’s condoling essays in *Thinking in Indian: A John Mohawk Reader*, restored my hope, as John Mohawk guides, “Culture provides the lens that lends meaning to what we see.” Oren Lyons an Onondaga faith-keeper in the foreword to “Thinking in Indian” honoured the life work of John Mohawk;

We depended on John Mohawk known as Sotsisowah (Corn Tassel) among his people, to translate that Native wisdom into the language of the colonizers. He was in my judgment the resident intellect of Iroquoia.

Jose Barreiro who lovingly compiled John Mohawk’s essays offers a fundamental framework gifted by John Mohawk in “Thinking in Indian;”

But there is also in our culture a core requirement that ultimately, whatever our beliefs are we are encouraged to maintain the tradition of *Clear Thinking*.

Canadians must be patient and tolerant as Indigenous peoples recover, restore and re-instate traditional pathways to healing and wellness even as new battles unfold over resource sharing, land claim settlements and the tragic travesty of FASD. Ongoing political battles over lands and resources have continued to circumvent the good life, good mind needs of those who are regarded as “in the way” of progress and Canadian economic development. Studying Canadian mining, forestry and water rights foretells more frontier towns of depravity, ecological destruction, drunkenness and human exploitation.

In January 2012, at a gathering of the Prime Minister and First Nations leaders, Prime Minister Stephen Harper when addressing the oppressive Canadian Indian Act spoke these powerful words; “To be sure our government has no grand scheme to repeal or unilaterally re-write the Indian Act: after 136 years that tree has deep roots-blowing up the stump would just leave a big hole.” Haudenosaunee peoples follow the “The Great Law of Peace” and the iconic representation of the “Great White Pine Tree” peace symbol. Long before there was colonization and an Indian Act, great civilizations flourished through-out Turtle Island. Prime Minister Stephen Harper’s reckless metaphoric reflections confirm the great peril Indigenous people continue to face in Canada. Abrams (1961) calls myths “widely held fallacies which serve explain why the world is what it is and why things happen the way they do.” Earlier, on September 25, 2009, Prime Minister Stephen Harper declared at a G20 Summit in Pittsburgh, Pennsylvania that Canada had no history of colonialism (AFN, Press Release, September 30, 2009), what myths informed his unfounded ruminations?

Prime Minister Stephen Harper perpetuates Canada rhetorical historical myths when he dismisses colonialism and discusses tree stumps blown up to satisfy the global drunken quest for spoils that has reached across the past 600 years, a timeframe that could easily be mythologized as Canada’s Dark Ages by Indigenous Peoples in Canada. We are inspired by words of hope such as those from the Honourable Frank Iacobucci who seeks paths to Truth and Reconciliation. Indigenous scholars and writers must provide the guidance to address tragic inter-generational trauma along with the destruction by colonial weapons like alcohol, the “Great Destroyer.” Canada’s Prime Minister can provoke “IdleNoMore, resistance while informed leaders like The Honourable Frank Iacobucci can create peace, friendship and respect to restore reciprocity, inter-dependency and non-interference between Canada and its Indigenous people. A Prime Minister’s apology is a testament to honour, but reckless rhetoric sustains a sad “false-face”.

Denis Foley writes about Haudenosaunee efforts around ceremonies to condole with new metaphors: “removing the fog that prevents one from seeing the truth, removing dirt from one’s ears so the story of the Iroquois people can be heard and washing the blood of the Iroquois people from the white man’s hands so that they may know the clasp of true friendship” (2010: 31). Foley reviewed the condolence ceremony of the Six Nations of the Grand River, the Haudenosaunee peoples, and the power inherent in these ceremonies to unite and strengthen the path forward. Haudenosaunee ceremonies and protocols to mourn collective disasters have great utility in addressing and soothing the severe societal complications of FASD, regarded by many as a direct implication of the foregoing history and continuing arrogance of the Canadian State. We, as an entire people, from every Nation, are truly responsible to produce clear minds and mend individual, community and First Nation suffering from the misuse of alcohol. The personal and social warfare in our territories where alcohol destroys future generations must stop. Foley reflects on the late Cayuga Chief Jacob (Jake) Thomas, a traditional wisdom keeper from Six Nations, and

the Condolence and Requicking Address to express the impacts of colonial practice in North America, Turtle Island, back to “those who are not honest allies” (Foley, 2010: 32). Chief Jacob Thomas could iterate words that would strengthen the resolve to fight the enemy of the unborn; alcohol addiction and historic intergenerational pain:

We hold in our hands fourteen strings of purple [strings of wampum]; these we hand, one by one, to you – authors of many [American/Canadian] history books, writers of cheap, inaccurate, unauthentic, sensational novels, and other writers of fiction who have poisoned the minds of young [Americans/Canadians] concerning our people, the Red Race of [America/Canada]; to the producers of many western cowboy and Indian television programs; to those treaty breakers who delight in dispossessing Indian Peoples by constructing dams on Indian Lands in violation of sacred treaties; and to those of this our country, who are prone to build up glory of our ancestors on the bones and life blood of our Old People,

With this string of wampum we take away the fog that surrounds your eyes and obstructs your view, that you may see the truth concerning our people. (Chief Jacob Thomas no date, Foley 2010: 32)

The Haudenosaunee condolence ceremony, observed to this day, called people to three principles: health of body and mind, and righteousness in conduct, equality and justice among people, and the maintenance of authority. Remember, after great colonial destruction came the grief and loss that Indigenous peoples continue to experience and perpetuate through the destructive forces of alcohol and FASD on the bodies and minds of subsequent generations. Ceremonies were, and remain integral to mourning rituals, and have long been regarded as “reciprocal civil protocols with profound significance at an individual level and also at a more general societal level” (Foley 2010: 27). These are ancient words of wisdom that we must all listen to and hear, because if not us, then who?

Alcohol is a great Destroyer...

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An Interdisciplinary Journal

Honoring the Voices, Perspectives and Knowledges of First Peoples through Research, Critical Analyses, Stories, Standpoints and Media Reviews

A Social Work student's developing understanding of Fetal Alcohol Spectrum disorder from medical and social perspectives and implications for practice

Andrew Wilson¹

¹ Masters of Social Work Student, Faculty of Social Work, University of Calgary, Alberta, Canada

Corresponding author: Andrew Wilson, wilsoal@ucalgary.ca

Abstract

Research on FASD has focused on medical/scientific findings (Gallicano, 2010; Jones, & Smith, 1973; Streissguth, Bookstein, Barr, Sampson, O'Malley, & Young, 2004). Continued medical research is thought to be helpful to our understanding of the origins of FASD and the interventions that help to address the psychosocial needs of persons with FASD. However, this paper stresses the need to also focus on the social aspects of FASD and the implications for human service workers who provide support for persons with FASD and their families. Gough and Fuchs (2006) indicate that although there is a growing prevalence of FASD-related disabilities, there is not a substantive knowledge base on child welfare practice in response to FASD. The need for human service workers to look beyond identifying a condition and addressing symptoms is emphasized. The author suggests human service workers need to prepare to work with children with FASD by reflectively appreciating the economic, legal, and cultural influences affecting persons as well as medically- and evidenced-based interventions.

Keywords: Fetal Alcohol Syndrome Disorder (FASD), medical perspectives, intervention, social support, human service workers.

Introduction

This literature review is a Canadian social work student's account of an academic learning experience about Fetal Alcohol Spectrum Disorder (FASD). FASD is a complicated problem garnering the attention of multiple perspectives. However, understanding FASD required, initially, exploring the topic from a medical and social perspective. Thus, the articles chosen for this review pertain to medical, legal, economic, and social issues associated with FASD, literature that demonstrates that FASD creates issues for society that require cultural considerations. The literature dates back to the 1970s when the syndrome appeared in North American medical literature, indicating FASD was first regarded as a medical problem, but slowly also became recognized as a legal, economic, and social justice issue. The knowledge learned about FASD resulted in considerations about the implications for practice by human service workers.

Fetal Alcohol Spectrum Disorder (FASD) is a term used to describe a broad range of disabilities that are caused by prenatal exposure to alcohol (Alberta Human Services, 2012). Children with FASD may have significant abnormalities ranging from alteration in memory, judgment, and executive function to intellectual disability (Chudley, Conry, Cook, Looch, Rosales, & LeBlanc, 2005; Masotti, George, Szala-Meneok, Morton, Looch, Van Bibber, Ranford, Fleming, & MacLeod, 2006). Chudley et al. (2005) and Fast and Conry (2009) suggest it occurs in 1-3% of live births. Understanding about FASD evolved from a medical approach to include a social perspective. Acknowledging the limited literature available on how to support persons with FASD, and focusing on the implications of FASD for human service workers, this paper indicates there is a need for helping professionals to have a greater understanding of the social perspectives associated with FASD.

Jones and Smith (1973) first used the term, Fetal Alcohol Syndrome (FAS) to refer to the problems seen in infants born from alcoholic mothers. Later, the syndrome began to be understood as a spectrum of disorders, and thus, was renamed Fetal Alcohol Spectrum Disorder (FASD). Both terms are used in this paper in an effort to match the terms used by each author in the literature; otherwise, FASD is used interchangeably to mean both FAS and FASD.

As a social work student I have been influenced by an innovative course on FASD and Child Welfare Practice at the University of Calgary, Faculty of Social Work. The course entitled, FASD and Child Welfare Practice, taught by Dr. Dorothy Badry, a faculty member involved with the Canada FASD Research Network for many years, helped me to understand the distinct needs of children and youth with FASD. I learned that the needs of children with FASD who receive child welfare services differ from the needs of other children, primarily due to the challenges that have brought them into care. As a result of taking this course, I developed a broad understanding of the Canadian response to FASD from medical, psychological, economic, and social perspectives. I became familiar with practice-based concerns related to FASD and have since applied this learning in my social work practice.

Medical perspectives

In the 1970s, emerging literature in North America focused on medical characteristics. Jones and Smith (1973) suspected alcohol contributed to problems in offspring. In writing about antiquity, Jones and Smith noted that “In Carthage, the bridal couple was forbidden to drink wine on their wedding night in order that defective children might not be conceived” (p. 999). They also draw our attention to a report submitted to the House of Commons in 1834 suggesting that offspring of alcoholic mothers were sometimes born with notably different physical features than offspring of non-alcoholic mothers. In their study, Jones and Smith noted several medical similarities between three infants born from mothers addicted to alcohol. These similarities included, but were not limited to, low birth weight and length, small eye openings, heart murmurs, joint and breathing problems, and clefts on the soft palate.

Root, Reiter, Andriola, and Duckett (1975) conducted a study on four children with the intent to see if growth abnormalities present in FAS could be caused by hormonal imbalances. All four children had heart murmurs. Three of the children were underweight and described as having similar facial features to the infants studied by Jones and Smith (1973). Root et al. concluded that growth abnormalities seen in the children were not caused by hormonal imbalances and suggested the children were underweight due to sub optimal nutrition and physically short in stature because of genetic factors.

Adding to the medical symptoms associated with pre-natal alcohol exposure, Stromland (1987) reported ocular abnormalities associated with FAS, suggesting up to 90% “of children suffering from the fetal alcohol syndrome have eye abnormalities, including malformation in the outer eye region, disorders of motility, and defects of different intraocular structures” (p.227). Stromland concluded there was an insufficient method to attribute abnormalities in children with FAS to a specific gestational period. In another study, Gabriel, Hofmann, Glavas, and Weinberg (1998) discovered alcohol in fact could disrupt and impair hormone levels in a mother and fetus. Additionally, Gabriel et al. suggested that growth hormones and insulin-related growth factors were also affected by alcohol, which offers a possible explanation for some of the growth related issues associated with FAS.

The link between FASD and epilepsy was strengthened by the work of Bell, Stade, Reynolds, Rasmussen, Andrew, Hwang, and Carlen (2010) who studied “the prevalence of epilepsy or a history of seizures in subjects with FASD” (p.1084). Bell et al. discovered a high prevalence of epilepsy (5.9%), compared to (0.6%) in the general population (Tellez-Zenteno, Pondal-Sordo, Matijevic, &Weibe, 2010). In one part of the study, 350 of the 425 were categorized by three specific FASD diagnoses; Fetal Alcohol Syndrome, Partial Fetal Alcohol Syndrome, and Alcohol Related Neurodevelopmental Disorder. Bell et al. found seizures were prevalent in all categories.

As a focus of this literature review the above medical symptoms and implications of FASD are important in the initial development of an understanding of FASD. Equally important, or more so, are the social and practice implications of FASD, beginning with a consideration of the interventions used presently in working with people who may have FASD.

Interventions

Presently, there is no cure for conditions related to prenatal alcohol exposure, making FASD a lifelong disability (Gallicano, 2010). From a psychosocial perspective, persons with FASD face adverse life outcomes (Streissguth, Bookstein, Barr, Sampson, O'Malley, & Young, 2004). Streissguth et al. noted that some of the psychosocial problems associated with FASD included “major disruptions in schooling, trouble with the law, inappropriate sexual behaviors, extensive confinements, and alcohol and drug problems” (p. 236). Challenging behaviors are addressed through structure and systematic teaching as potentially effective methods for children with FASD. A predictable environment supports a child diagnosed with FASD to better connect daily activities. Achieving a structured environment includes making a daily schedule and keeping it fairly consistent, striving for low amounts of ambiguity in instructional methods, and making the connections between different instructional methods consistent and clear. In addition, Kalberg and Buckley (2007) support teaching that decreases visual and auditory distraction with activities that are organized visually.

Illustrating the need for structure for children with FASD, Kalberg and Buckley (2007) indicate the school environment can be daunting and difficult to successfully navigate, academically and socially, making the school a negative experience for the child with FASD. Kalberg and Buckley suggest “helping the child to metacognitively understand his/her learning style and challenges may assist in the child’s ability to moderate his/her own behavior appropriately” (p. 284). They also promote structuring and systematic teaching techniques appropriately tailored to each child to create predictability and understanding for the student. The sense of safety, comfort, and confidence is thought to result in the child’s willingness to take more risks, resulting in increased skill development and a more positive sense of self.

Historically, research on FASD has focused on medical/scientific findings (Chudley et al., 2005; Gabriel et al., 1998; Gallicano, 2010; Jones, & Smith, 1973; Root et al., 1975; Streissguth et al., 2004; Strömmland, 1987; & Tellez-Zenteno et al., 2004). Although continued medical research is helpful to our understanding of the origins of FASD, it is also important to examine interventions that help to address social issues and the implications for human service workers who provide support for persons with FASD and their families. Human service workers who respond to the needs of children with FASD need to be knowledgeable and informed to promote good practice. We also need to understand the root causes of FASD to help resolve what may be a preventable social problem.

Social perspectives

One way to obtain an essential understanding of how FASD has become a social concern is to view the development of FASD from a social, as well as a medical perspective. Socially, the use of alcohol historically influenced the development of FASD as illustrated in the following quote:

Parents gave it [alcohol] to children for many of the minor ills of childhood, and its wholesomeness for those in health, it appeared, was only surpassed by its healing properties in case of disease. No other element seemed capable of satisfying so many human needs. It contributed to the success of any festive occasion and inspired those in sorrow and distress. It gave courage to the soldier, endurance to the traveler, foresight to the statesman, and inspiration to the preacher. It sustained the sailor and the plowman, the trader and the trapper. By it were lighted the fires of revelry and of devotion. Few doubted that it was a great boon to mankind (Levine, 1983, p.115).

What the above quote suggests is that alcohol is an entrenched, and rightly or wrongly, celebrated characteristic of society historically. However, the effects alcohol has had on society are generally understood to not be entirely positive. For example, the social impact and destructiveness of alcohol and alcohol addiction presents critical issues within society, as noted in the following discussion about social challenges presented by FASD.

International and national economic challenges

FASD is an international issue due to the global availability of alcohol and the economic costs associated with managing and preventing FASD-Related disabilities. Drabble, Poole, Magri, Tumwesigye, Li, and Plant (2011) wrote on the efforts of the United States, Canada, the United Kingdom, Uganda, Uruguay, and China to prevent FASD. The fact these countries include the world's two largest economies, the United States and China, and two other leading world economies, Canada and the United Kingdom, make it apparent that FASD has a socioeconomic global impact. May et al. (2011) found that accurate estimates regarding the prevalence of FASD are lacking in western countries, and that the frequency of FASD may be higher in western countries than previously thought. May et al. did an epidemiology study in Italy where alcohol is consumed with meals and found that estimates were significantly higher than previously suggested, raising the question of whether FASD is more prevalent in western society than previously estimated. Yet, although knowledge about FASD has been far reaching, efforts to combat this problem are not coordinated internationally, such as the efforts to control disease through massive vaccinations in the interest of prevention of health problems.

The United States, by 1988, were spending four billion dollars annually on costs associated with FASD (Harwood, 2000, cited in Lupton, Burd, & Harwood, 2004). It is worthwhile noting that FASD is a preventable disability and the above expenditures could be applied to other social needs if the prevalence of FASD could be significantly reduced globally. Chuck Lupton, Substance Abuse and Mental Health Services Administration (SAMHSA), FASD Center for Excellence, advanced the thought of FASD as an economic concern. Lupton et al. (2004) listed several cost estimates regarding FASD, all of which were high, and concluded that at the very least the high costs associated with FASD easily justified extensive prevention efforts. For example, the lifetime cost of FASD in the US was estimated to be 596 thousand per person in 1980 (Harwood & Napolitano, 1985, cited in Lupton et al., 2004). Taking inflation into account, Lupton et al. predicted that as of 2002 the average lifetime cost per person with FASD would be approximately 2 million dollars.

Stade (2003) indicates that a conservative estimate suggests Canada alone spends over 340 million dollars annually to manage FASD. This estimate was limited to people diagnosed with FASD who fit into the category of 21 years of age or younger. The cost of FASD in Alberta is thought to be between 10 and 30 thousand dollars per person annually, with the family expected to pay 19 – 20% (Thanh & Johnson, 2009). Care plans that cost 2000–6000 dollars a year over the normal costs of raising children present a barrier for the potential adoption of children in care in jurisdictions in which adoptive parents are responsible for medical costs associated with the adopted child. Farris-Manning and Zandstra (2007) noted that “experts estimate 50% of the 6,600 kids in care in Alberta [1999] have FAS [Fetal Alcohol Syndrome]” (p.15). Each one of these children costs the taxpayer approximately 3 million dollars over the lifetime of the child (Jacobs, 1999, cited in Farris-Manning & Zandstra. Fuchs, Burnside, Marchenski, and Mudry (2007) who note the increasing amount of children with FASD coming into the Manitoba child welfare system, comment:

Because children with FASD enter the child welfare system at a younger age and spend a greater proportion of their lives in care than other children, their needs present an additional challenge to the child welfare system. The data on the increasing number of children coming into care and the prevalence data from the Addictions Foundation of Manitoba indicates an increasing degree of urgency for health, education and the child welfare systems to develop effective integrated health and service policy and programs to respond to the growing numbers of children and families with FASD (p.37).

The high costs associated with managing a child with FASD in state care and the increasing prevalence of children with FASD in state care, in provinces such as Alberta and Manitoba, suggest that FASD has become a critical issue in child welfare practice.

The above literature related to the financial costs of FASD focuses on total yearly government spending as well as yearly spending by people and families living with FASD. Figures pertaining to total overall national spending are arrived at, in a summative sense, by taking the estimated costs of a single instance of FASD, and multiplying that number by the estimated amount of people born with FASD yearly. Apparently missing from the literature are the personal accounts of the financial impacts of FASD from the very people that are living with the disorders. Moreover, it would be interesting to know if the financial costs associated with FASD are realistically affordable throughout the general population of North America. More research is needed around the financial burden of FASD on a personal and community level that encompasses the voice of people living with Fetal Alcohol Spectrum Disorder.

Legal issues

In Canada, FASD is over represented in the criminal justice system (Fast & Conry, 2009). If the same is true of other countries, it could be concluded that people with FASD represent a diverse globally oppressed population, crossing all cultural, ethnic, as well as international boundaries. Given that alcohol is accessible and consumed during pregnancy, there will always be persons with FASD who, without interventions, may be incarcerated for actions caused by their disability (Fast & Conry). Fast and Conry advanced the research on FASD, indicating how it affects the legal system by reporting on FASD in the Canadian criminal justice system. They found the occurrence of persons with FASD in the criminal justice system appears to be far more significant than the estimated prevalence of 1-3% of the population (Fast et al., 1999, cited in Fast & Conry).

Fast and Conry (2009), in reviewing the criminal justice system and its effectiveness regarding housing people with FASD, came to the conclusion that the life-long neurological impairments found in people with FASD included “learning disabilities, impulsivity, hyperactivity and poor judgment, increase susceptibility to criminal behavior and victimization” (p. 256). Fast and Conry maintained that “offenders with FASD should not return to the community, after release, worse off than when they left, due to misunderstanding, victimization, and mismanagement of their disabilities” (p. 256). In order for the criminal justice system to properly accommodate FASD, Fast and Conry suggest that professionals should be subject to ongoing training regarding recognition and diagnosis of FASD as well as the ethical and cultural issues that arise in addressing the social and legal implications of FASD. It should be noted as a logical inference that increasing the judicial system’s ability to accommodate FASD must include increasing the understanding of why FASD is over represented in the criminal justice system, and subsequently, increase appropriate alternatives other than incarceration. Otherwise, the overrepresentation of FASD in the criminal justice system will not be addressed. To build this understanding, we need to go beyond surveys, straight to the narratives of inmates with FASD. Perhaps this way, we can gain insight into why people with FASD are at a higher risk of incarceration.

While the literature of the 1970s focused largely on the medical identification of FASD, the 1980s appeared to be the decade in the United States in which some US state legislatures slowly began to address, legally, the social issues associated with FAS. Ris (1988) reported that in 1985, 1987, and 1988, Wisconsin, Oregon, and Rhode Island, passed laws requiring information on FAS to be distributed with new marriage licenses. Efforts by these three states seemed to mark the beginning of state and thus, social involvement, in FAS prevention in the US. Ris indicated that no other US state, at the time the article was written, had successfully passed laws aimed at preventing FAS.

A further examination of laws pertaining to FAS and the state of Wisconsin indicated the Wisconsin legislature amended the state’s child protection laws by adding a FAS provision (De Ville & Kopelman, 1999). The change meant that Wisconsin judges could “confine pregnant women who abuse alcohol or drugs for the duration of their pregnancies” (De Ville & Kopelman, p. 332). In criticizing the law, De Ville and Kopelman wrote “Wisconsin’s fetal protection law collapses an issue involving individual maternal liberty into a revamped child abuse law, complicating the already intricate medical, moral, and social problem of substance use during pregnancy” (p.340). The law passed by the state of Wisconsin is significant as it supports a trend in child welfare in which some US states favored the protection of an unborn child over the liberty of the mother.

Bracken (2008) points out that the over-representation of Indigenous persons in the Canadian criminal justice system is also connected to discrimination, historical influences, and broader health and social development issues. Bracken suggests that FASD and the Canadian criminal justice “are often considered in the public mind as almost uniquely Aboriginal problems” (p. 26). Bracken points out that “this is a misconception born out of the percentages of aboriginal people involved in the criminal justice system in Canada” (p. 26). Similarly, Fast and Conry (2009) conclude FASD is overrepresented in the criminal system. The above accounts of Indigenous representation in Canadian criminal justice suggest FASD relates to the stereotyping of Indigenous people without concurrent analysis of FASD in White/Caucasian families as well as families in other backgrounds. Further research by Indigenous scholars is required to avoid potential discriminatory and stereotypical accounts by researchers from a dominant culture. Such research is essential in training human service workers to avoid thinking of the abuse of alcohol by a particular segment of the population, such as Indigenous people, in a stereotypical manner without the context in which it may occur.

Cultural considerations

Culture is made up of norms, values, beliefs and ideals. The culture of the dominant group in society is presented as the universal cultural norm and suppresses or represses subordinate cultures (Mullaly, 2010). Mullaly suggests that when reflecting on another's behavior human service workers strive for cultural sensitivity by increasing their awareness of personal cultural influences in aiming to establish a helping relationship. Otherwise, human service workers can act in an oppressive manner by viewing a situation from a dominant group perspective, using its culture as the norm to analyze others (Mullaly). Mullaly explains that the tendency to apply a dominant group perspective to other cultures is so pervasive that the stereotyping that results is not questioned; for example, when black people are viewed as drug addicts and Indigenous people are seen as alcoholics. Thus, dominant group members fail to see the experience of the less dominant and "imposes on the oppressed group its experience and interpretation of social life" (Young, 1990, cited in Mullaly, p. 60).

Salmon (2011) explains how the dominant group in society fails to see how they oppress those who are less privileged. She suggests that in recent decades the Canadian government has increasingly focused and campaigned for the need to prevent FASD in Indigenous communities without sufficiently addressing systemic health inequities, such as poverty, racism and differential access to resources. Salmon (2011) points out that campaigns spearheaded by the Canadian government to promote the health of children, often use the same mediums of radio and print to educate the public on proper child care. Salmon notes that although radio and print media are expensive, using these methods to inform the public is far cheaper than addressing the root causes of systemic health inequalities, such as poverty. Salmon insists that campaigns to prevent FASD must be understood as emerging from a social, political and historical context. For example, Salmon writes about how the issue of patriarchy and mother blaming becomes more alarming in the context of Indigenous motherhood. Salmon discusses the conservative view that the health of a nation is the wealth of a nation, and therefore, women are responsible for producing healthy babies, and thus, are logically primarily responsible for a nation's general wealth. Salmon describes how Canada has a long history of emphasizing the female responsibility to have a healthy pregnancy and baby, "by avoiding alcohol, tobacco, and other drugs" (p. 168). Further, Salmon considers the impact of overrepresentation of Indigenous children with FASD in the Canadian child welfare system, suggesting it is a major factor in creating the stereotypical view of Indigenous mothers as "abusive, neglectful, and otherwise dangerous to their children" (Salmon, 2011, p. 169). Salmon describes this oppressive stereotyping as being the result of transferring white middleclass expectations of motherhood onto a, on average, far less affluent minority population by western standards (Salmon).

Tait (2003) states that less than one percent of the estimated populations believed to have FAS are diagnosed in Canada, pointing out that clinical, diagnostic inconsistency are common and that epidemiological evidence is inconclusive and/or methodologically questionable. However, Tait advises us that there is a sense of urgency in North America, leading to campaigns to stop all pregnant women from drinking alcohol. By drawing attention to the motivation behind the discourse, the grounds upon which it is legitimated and the implications it has on the lives of Indigenous women, Tait clearly supports the idea of the social construction of FAS.

Salmon (2011) reminds us that women who give birth to children with disabilities face stressful, caregiving responsibilities with limited social support, often finding it difficult to work and opting, out of necessity, to live on social assistance. Additionally, Salmon points out that Indigenous women may self-medicate with alcohol to contend with the trauma associated with the experience of residential schools, the removal of children from their care when they acknowledge a problem with substance abuse, and the lack of social, economic, political, and cultural opportunities.

Astley, Bailey, Talbot, and Claren (2000) contributed an important study in raising the issue of birth mothers and adding to the knowledge and deeper understanding of women's lives in relation to giving birth to children with FASD. Astley et al. suggest that the women most likely to have a child with FASD are unlikely to reduce their alcohol use on their own. They found that all 80 women in their study had addictions to alcohol that were connected to histories of severe physical, sexual and emotional abuse. Eight per cent reported living with violent males, unsupportive by any efforts to quit drinking during their pregnancy. Most of the women had endured isolation from community and family, poverty, and loss of previous children to child welfare agencies. These findings indicate that prevention programs that advertise the harmful effects of drinking alcohol while pregnant need to be coupled with other interventions. Thus, Canadian public health campaigns that simply suggest women stop drinking are inadequate and mainly serve to support stereotypical reaction that views mothers as solely responsible for a child born with FASD.

Research and the development of interventions have possibly been impeded by historical cynicism about researchers and workers. Specifically, it is conceivable that identifying the prevalence of FASD among Indigenous people may contribute to discrimination and oppression in ways that end up promoting misunderstandings about the incidence of FASD within Indigenous communities. In looking for ways to interact successfully with Indigenous communities, Masotti et al. (2006) suggest greater success can be accomplished by using a participatory action research (PAR) approach that involves concurrent collaboration between researchers and community members in the goal to create positive social action. PAR provides an option to develop interventions for FASD by capitalizing on the strengths of Indigenous communities by allowing community members to develop, implement and evaluate interventions, with researchers as collaborators in the documentation process.

The impact of colonial policies toward Indigenous people, and in particular the legacy of discrimination, forced assimilation and economic marginalization, must be considered when intervening and responding to Indigenous persons with FASD. The test for practitioners and policy makers is to develop ways of identifying FASD which does not perpetuate the stereotypes of Indigenous peoples.

Implications for human service workers in child welfare

Although Gough and Fuchs (2006) indicate that there is a growing prevalence of FASD-Related disabilities, there does not appear to be a substantive knowledge base in the literature on child welfare practice in response to FASD. There is literature related to child welfare practice that is generally applicable to all children, including such topics as working with children with disabilities and benefits of cultural matching in foster care and adoption (Brown, George, Sintzel, & St. Arnault, 2009). However, Bohjanen, Humphrey, and Ryan (2009) undertook an extensive literature review that focused on

evidenced-based interventions intended for children and youth with FASD and found only three studies fit their criteria. Further, Premji, Serrett, Benzies, and Hayden (2004) reviewed literature for a similar purpose and found only ten studies which met their criteria. Although there is some literature pertaining to child welfare practice in response to FASD, it does not appear to be as substantive as, for example, medical-related literature. As children with FASD tend to enter the child welfare system at a younger age, and spend a greater proportion of their lives in care than other children (Fuchs, Burnside, Marchenski, & Mudry, 2007), human service workers need to prepare and become knowledgeable about the needs of children with FASD for whom they will inevitably provide service.

Fast and Conry (2009) note that although some training for human service workers who work with persons with FASD is happening, they insist there is a need for human service workers to have a greater understanding of the symptoms and interventions particularly relevant to FASD. For example, a certificate program is offered through Lethbridge College, to address a growing demand for support workers and caregivers to support children and adults with FASD, and for current professionals in various human service areas (Fetal Alcohol Spectrum Disorder Education, 2013).

Regulated, continuing professional curriculum about FASD is required for professionals involved in the criminal justice system. It is suggested that if professionals in the legal system can recognize FASD early, and are knowledgeable about the most appropriate interventions, the result may be a reduction in the overrepresentation of FASDs in the criminal justice system (Fast & Conry, 2009).

Fuchs et al. (2007) stress there is an immediate need for health, education and child welfare systems to develop and deliver integrated programs and services. For example, Alberta has a FASD 10-Year Strategic Plan which has resulted in the mobilization of local support networks. These support networks offer community-based coordinated assessment and diagnosis, targeted prevention, and support services for people affected by FASD and their caregivers. The implementation of the 10 year plan and the rise of local support networks is evidence the system is trying to respond to the social needs associated with FASD.

As a general rule, human service workers can justify a referral for a diagnostic assessment, for children, when characteristic symptoms of FASD are reported. Presently, there is no known solid system to diagnose adults. Potential indicators that an assessment is appropriate include a history of family alcohol problems, care providers other than the birth mother, attendance at special education classes, a previous diagnosis of attention deficit hyperactivity disorder, different home placements, suspensions from school, and friends from a different age group (Kellerman, 2005). When it is unknown if a child has been prenatally exposed to alcohol, concerns that may be visible or reports of concern by a parent or care provider may prompt a medical referral. Knowledge about FASD is critical for human service workers who work with children and youth who exhibit psychological/psychosocial and behavioral issues associated with FASD. These problems include trouble in school and with the law, cognitive and emotional issues, learning disabilities, alcohol and drug problems, memory problems, inappropriate sexual behaviors, poor organizational abilities, and focusing difficulties (Streissguth et al., 2004).

Initially, a knowledgeable worker may suspect FASD in a child client and refer the child for an assessment, creating the possibility of an early diagnosis and intervention. Once the diagnosis is obtained, human service workers knowledgeable about FASD can help monitor interventions to ensure children with FASD get the supportive assistance they need. Such a supportive environment would include sufficient structure in the home with in-home supports, if needed, and educational help with developing life skills by constructing the environment around the child's strengths.

Human service workers need to deliver services in a culturally sensitive manner as well as be cognizant of the medically-based needs of children in their care. Improving the quality of life, for the long term, for any person with a disability logically requires sufficient knowledge pertaining to the personal and social challenges the disabled person will face (Goodley, 2011; Meekosha & Dowse, 2007; Rothman, 2003). From a best practices perspective, human service workers who have knowledge of the historical, medical and social issues associated with FASD will be better prepared to provide appropriate interventions from a critically sensitive perspective. Workers knowledgeable and sensitive to cultural implications need to avoid unintentionally putting a birth mother in a position of being blameworthy, placing the mother at more risk of further psychosocial trauma.

Practically, human service workers can assist the family with a referral process to obtain a diagnosis and interventions by helping to educate the family on available services. They can offset the influence of the medical model with its emphasis on defining a problem and focusing on a cure with a social model that concentrates on social support for the person with FASD and their family. In child welfare, human service workers can dispel fears of apprehension by demonstrating they are present to help empower families with advocacy strategies in securing the required respite and supportive interventions needed. Extended family and friends can be included wherever and whenever possible in providing support and structure. Knowledge of FASD that is practical and focused on the needs for this population would be helpful. These measures help to initiate a pathway for success that is tailored with goals and objectives that meet a particular family's needs and abilities.

The education of human service workers should include knowledge of available supportive services and how to advocate for needed services (Fuchs, Burnside, Marchenski, & Murdy, 2010) as well as recognition of symptoms and knowledge about interventions. In supporting human service workers, there needs to be more research on the needs of children with FASD. More support for women struggling with addictions (Salmon, 2011) is needed to make it possible for parents to continue to be involved with their children and for children in the care of child welfare to return to their families of origin. Human service professionals should also play a role, along with persons with FASD and their caregiver, in developing policies for intervention and to further educate the public in preventing FASD and reducing stigma associated with FASD. In summary, exploring the history of FASD helps human service workers to see FASD as a complex issue that affects persons with FASD and their families medically, economically, legally, and socially, requiring knowledgeable workers who use appropriate interventions while exercising critically reflective practice.

Conclusion

Most of the literature about FASD focuses on medical/scientific findings pertaining to prenatal alcohol exposure, important in ascertaining an early diagnosis and intervention (Gallicano, 2010). A review of the literature indicates how FASD expanded from largely medically-based research into economic, legal, and cultural considerations that required human service workers to exercise informed, critical, and reflective practice when intervening with persons with FASD. Medical knowledge and ongoing research about FASD is important but fails to connect to the social causes of FASD or suggest what knowledge and skills are beneficial to help those with an incurable chronic condition. The literature indicates that people with FASD need structure in their daily lives. However, the literature did not illustrate how human service workers should apply practice skills in helping persons with FASD and their families to create more structure in their daily routines to manage FASD; thus, highlighting a critical gap in published research in this area.

The literature also indicated concern about existing FASD prevention initiatives in Indigenous and other minority communities. Salmon (2011) suggests that FASD initiatives are designed for the majority in Canadian culture, and when applied to Indigenous communities, are more oppressive than helpful. For example, Salmon reports that if Indigenous women come forward requesting help regarding alcohol abuse, their children are often apprehended. Knowing that apprehension of their children may be the result of asking for help Indigenous mothers may very well refrain from asking for assistance (Astley et al., 2000).

More research regarding the social realities of FASD needs to happen, providing a knowledge base for intervention. Future research should focus on what works best with Indigenous families and communities with an emphasis on an Indigenous worldview and a methodology that uses a storytelling approach that provides feedback regarding more appropriate interventions. We need to move away from outcome-based research, such as surveys or risk assessment, to research that reflects the experience of the Indigenous community, such as narrative inquiry or participatory action research.

With appropriate knowledge and training we can effectively work to decrease the structural oppression evident in some of the interventions presently used. Clearly, FASD is a substantial issue that should garner adequate attention from training institutions. Human service workers trained on FASD, as well as other disabilities, will contribute to informed service for children with complex needs. Thus, it is essential post-secondary education prepare students in human service programs for their coming encounter with FASD with appropriate curriculum that is practical and culturally sensitive.

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An Interdisciplinary Journal

*Honoring the Voices, Perspectives and Knowledges
of First Peoples through Research, Critical Analyses,
Stories, Standpoints and Media Reviews*

Bound by the clock: The experiences of youth with FASD transitioning to adulthood from child welfare care

Linda Burnside,¹ Don Fuchs²

¹ Avocation: Counselling, Consulting, Research & Training, Manitoba, Canada

² Faculty of Social Work, University of Manitoba, Manitoba, Canada

Corresponding author: Linda Burnside, linda@avocation-ccrt.org

Abstract

Fetal Alcohol Spectrum Disorder (FASD) is a condition that affects a significant proportion of children and youth in the care of child welfare agencies in Canada. Few studies have heard from the voices of youth with FASD themselves as they are leaving care. This article describes a qualitative study that focuses on the lived experiences of 20 youth with FASD in Manitoba as they were preparing for the transition from child welfare care to adulthood (or had recently emancipated from the system). The experiences and insights of these youth highlight the supports and services required by youth with FASD transitioning out of care, from both the child welfare system and from services for adults with FASD.

Introduction

Fetal Alcohol Spectrum Disorder (FASD) has been recognized as one of the leading causes of preventable birth defects and developmental delay in children in Canada (Canadian Pediatric Society, 1997). FASD is the umbrella term used to describe the range of conditions caused by alcohol-exposed pregnancies (Paley, 2009; Warren et al., 2004), including Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), partial FAS (pFAS), alcohol-related neurodevelopmental disorders (ARND) and alcohol-related birth defects (ARBD). FASD results in a wide range of impairments on a continuum from mild to severe, with considerable variation in the effect on individual functioning (Abel & Hannigan, 1995; Barr & Streissguth, 2001), with both direct effects on functioning as a result of prenatal brain damage and secondary effects as a result of coping strategies to manage environmental expectations (Malbin, 2004).

In recent years, much attention has been given to the issues confronting youth who age out of the child welfare system and the deleterious outcomes experienced by many of these youth have been well documented (Reid & Dudding, 2006). Research shows that adolescents who are emancipated from the child welfare system at age of majority are more likely than those who have never been in care to be undereducated, experience homelessness, become a young parent, be unemployed or underemployed, if

employed to have earnings below the poverty line, be on social assistance, be incarcerated or involved with the criminal justice system, have mental health issues, and be at high risk for substance abuse issues (Courtney, Dworsky, Lee, & Raap, 2010; Tweedle, 2005). Youth with disabilities who are also in care face even greater challenges as they reach emancipation. In addition to the adverse outcomes experienced by many youth in care as they leave the system, youth with disabilities endure more placement breakdowns than other youth in care (Geenen & Powers, 2006), and are less likely to complete high school, pursue post-secondary education, or find gainful employment (Geenen, Powers, Hogansen, & Pittman, 2007). Being a youth with FASD results in further complications, such as needing supported living arrangements in adulthood, life skills training, and support services for mental health issues and addictions (Child and Youth Officer of British Columbia, 2006).

It is also well documented that Aboriginal children are significantly over-represented in child-in-care populations across the country, especially in the western Canadian provinces (Blackstock, 2007; Blackstock, Prakash, Loxley, & Wien, 2005; Blackstock, Trocmé, & Bennett, 2004; Canadian Council of Child and Youth Advocates, 2011). Aboriginal children come into care more frequently, partly as a result of the presence of multiple risk factors such as poverty, oppression, compromised parenting abilities as a result of the impact of the residential school system, and other social, economic and cultural variables (Fluke, Chabot, Fallon, MacLaurin, & Blackstock, 2010). These variables can lead to the use of alcohol to cope with adverse life conditions, with substance use during pregnancy a risk factor for the occurrence of FASD (Pacey, 2010).

While several studies have confirmed the risk of adverse outcomes for individuals with FASD, this study is unique in its effort to hear directly from the youth themselves and learn their needs to manage the transition to adulthood from child welfare care more successfully. Hearing the perspectives of these youth is critical for child welfare agencies, given the parental responsibility the child welfare system has taken on for so many youth with FASD under child welfare guardianship. These insights can inform policy development and service delivery, as well as set the stage for future outcomes research to assess how supports can make a difference for youth in care transitioning to adulthood including: attainment of early adulthood milestones (education, employment, life skills, personal autonomy, etc.), and reduction of more costly, problem-oriented services (such as criminal justice involvement, adolescent pregnancy services, reliance on income assistance, addictions treatment, and/or intensive mental health services).

Brief literature review

Adolescence is a challenging stage of development for youth, characterized by the tasks of physical maturation, identity formation, exploration of close relationships with peers, and achieving independence and autonomy (Christie & Viner, 2009). Recent research suggests that the process of maturation continues into early adulthood as the parts of the brain responsible for impulse control, emotional regulation, delaying gratification, and resistance to peer influence do not fully mature until an individual reaches his or her mid-twenties (Magyar, 2006; McGregor, 2009; Steinberg, 2007). Middle adolescence (age 15 – 17 years) is characterized by experimentation and risk-taking behaviours; in contrast, late adolescence (age 18 – 21 years) is marked by greater capacity for planning for long-term goals and incorporating a stronger sense of personal values (Christie & Viner, 2005). Contemporary families often afford adolescents and young adults a lengthy period of time to explore various roles and identities (e.g.

trying out different jobs, post-secondary education, dating relationships) in an emotionally and financially supportive environment that fosters identity formation well into early adulthood.

Youth in care, however, are often pressured to complete these developmental tasks before they reach legal age of majority, the age that often necessitates leaving child welfare care to live independently (Kools, 1997). Adolescents in care may be forced to complete the task of identity formation prematurely and at an earlier age than their peers who have not grown up in care. Additionally, Aboriginal youth often also have to deal with the developmental task of identity formation in disconnection from their family of origin and cultural heritage, which exacerbates identity integration. As Kools (1997) explains, “without a socially sanctioned or supported time frame for identity experimentation, identity development may be interrupted, incomplete, and potentially damaged or foreclosed” (p. 269). Consequently, youth transitioning from care at age of majority experience “a frustrating paradox, where they have little or no opportunity to practice skills of self-determination while in care, but are expected to suddenly be able to control and direct their own lives once emancipated” (Geenen & Powers, 2007, p. 1090). Although remaining in care past age of majority is increasingly recognized as an important opportunity to support the adolescent’s more complete psychosocial development (Courtney, Dworsky, & Peters, 2009; Rutman, Hubberstey, & Feduniw, 2007), many youth find that the child welfare system does not recognize or support their need for independence and autonomy within a child-oriented structure once they reach legal adult age (McCory, McMillen, & Spitznagel, 2008).

A high proportion of youth with FASD grow up in child welfare care (Besharov, 1994; Fuchs, Burnside, Marchenski, & Mudry, 2005), and these youth experience even greater challenges as they navigate the developmental tasks of adolescence. The effects of FASD on an individual’s functioning have been characterized as both primary and secondary in nature (Malbin, 2004). Primary effects refer to the direct impact of damage incurred to the brain as a result of prenatal exposure to substances and include difficulty with executive functioning tasks (planning, organizing, setting goals, and following schedules, for example), memory problems, impaired judgement and decision making, difficulty with change and transitions, and impulsivity. Secondary effects are behaviours that develop in reaction to, and as a way of coping with, the primary disability, including fear and anxiety, poor self-concept, pseudo-sophistication, school behaviour problems, depression, frustration, aggression, and trouble with the law. By the time an individual with FASD reaches adolescence, these secondary behaviours may have become well established patterns with harmful outcomes (Malbin, 2004).

The impact of FASD is also mediated by environmental factors, such as living with an alcoholic parent or being subjected to child abuse or neglect, or other adverse life conditions such as poverty (Streissguth, Bookstein, Barr, Sampson, O’Malley, & Young, 2004), factors which often lead to child welfare’s involvement and a child’s admission to care. This is a particularly salient point as it pertains to Indigenous populations, who frequently are affected by low socioeconomic status and the drinking patterns that are associated with coping with impoverished living conditions (Abel & Hannigan, 1995; O’Leary, 2003), conditions which can contribute to the occurrence of FASD.

A number of protective factors have been identified that can help to ameliorate the damaging effects of FASD. These protective factors include the early diagnosis of FASD which can aid in responding more appropriately to the child's behaviour (Streissguth et al., 2004), a steady caregiver who understands the disability (Graef, 1998), a stable and nurturing home environment (Streissguth et al., 2004), and adjustments to the environment to meet the child's needs rather than expecting the child to adapt to the environment (Malbin, 2004).

However, the secondary behaviours resulting from FASD may exacerbate the issues facing youth in care throughout adolescence and compromise these protective factors. Placement breakdowns occur with concerning frequency, especially in adolescence (Geenen & Powers, 2006; Hyde & Kammerer, 2009), disrupting school stability and increasing the drop-out rate for youth in care (Courtney & Hughes Heuring, 2005; Stott & Gustavsson, 2010), and contributing to a higher incidence of aggressive and anti-social behaviour (Ruest, 2000). Youth with FASD in care are also at high risk for mental health issues and substance misuse (Child and Youth Officer of British Columbia, 2006). Throughout these experiences, key relationships with caregivers, peers, teachers, and communities are also broken, leaving youth with little feeling of belonging or a focus of control in their lives (Stott & Gustavsson, 2010). As youth reach age of majority, many seek out relationships with biological family members, partly to make sense of their identity but also to replace formal relationships with foster parents, social workers, and other professionals that often end in adulthood (Collins, Paris, & Ward, 2008), only to find that family members may be still struggling with the issues that initially led to the involvement of the child welfare system.

In summary, youth in care with FASD face daunting obstacles to their future success posed by the dual challenges of being in care and coping with their disability. Both the primary effects of brain damage from prenatal alcohol exposure and the secondary behaviours resulting from a poor fit between the individual and their environment complicate the needs of adolescents with FASD, especially as they reach age of majority and are conferred with the immense responsibilities of emancipation that are not congruent with their abilities.

The voices of youth with FASD leaving care

Methodology

This study involved semi-structured qualitative interviews of youth with FASD who were in care of Manitoba's child welfare system to hear about their experiences of transitioning out of care with their disability. Child and Family Services agencies in the province were sent an information package about the project with a request to distribute invitation letters to youth with a diagnosis of FASD who were permanent wards (or who had been in long-term care until adulthood) between the ages of 16 and 21 years of age. Interested youth contacted the researchers directly to arrange an interview. A consent form was signed by the youth and, if they were currently in care, co-signed by their caseworkers. A gift card to a local department store valued at \$50 was given to each youth who participated in an interview. Interviews were digitally audio-recorded, transcribed, and then analyzed with the NVivo computer software for qualitative research. The constant comparison method was utilized to identify themes and categories that emerged from the youths' narratives.

Limitations

Due to the challenges in recruiting youth with FASD to talk about their personal experiences, the findings of this study are based on a small group of participants whose perspectives may not be generalizable to a wider population. Formal confirmation of a diagnosis of FASD was not sought from the participants or their caseworkers; referrals were accepted on the basis of the identification of FASD by the young person and his/her caseworker. Although care was taken to ensure that participants understood the questions they were asked in interviews by phrasing questions in plain language and restating in alternative words to enhance clarity, it is possible that their disability affected their interpretation of the questions or influenced how they responded to questions. Finally, information provided by the youth such as length of time in care or number of placements was not cross-referenced with agency records.

Demographic portrait of the youth participants

Interviews with twenty youth ages 16 to 21 were included in the study, ten males and ten females representing all four Child and Family Services Authorities in Manitoba: one from the Metis Authority, three from the General Authority, five from the Northern Authority and eleven from the Southern Authority. The majority of youth were of Aboriginal descent (90%). Twelve of the youth lived in urban settings, seven lived on reserve, and one lived in a rural area. Fourteen of the participants were still in care at the time of the interviews, with nine under the age of 18 and five in an extension of care past age of majority (the age of 18 in Manitoba). Four youth who had left care at the time of their involvement in the study had received an extension of services prior to emancipation from the child welfare system.

Eight youth reported entering care prior to age one, nine reported they were admitted to care between the ages of one and six, and three came into care around age twelve. Half of the youth had experienced between two and five placements, six had between six and ten placements, two had between eleven and twenty placements and one reported more than twenty placements.

More than half of the youth (eleven) reported that their longest placement had lasted more than ten years, although four of these placements had broken down in adolescence. Six youth stated that their longest placement was less than two years while three reported placements lasting between three and five years.

Six of the ten female participants had a child, and two of these youth were pregnant with their second child at the time of the study. Nine of the twenty youth were still in school, with three having returned to school after a period of disruption in their education. Two youth had completed high school with no disruptions in their schooling. The remaining nine adolescents had left school without completing high school and were not currently enrolled in school.

Findings

The perspectives shared by the adolescents in this study reveal a compelling description of the lives of youth with FASD in child welfare care, a story that has rarely been told by youth themselves. Their experiences are critical for child welfare agencies and foster parents to understand. Further, those who form policy and legislation and develop programs will benefit from understanding the experiences of these youth, in order to ensure that services and policy frameworks are best suited to meeting their needs. The results of this study can be organized around five main themes: (a) the role that FASD plays in the lives of adolescents in care; (b) the critical need for consistent relationships; (c) developmental experiences for youth with FASD; (d) challenges in adolescence; and (e) transition planning for youth with FASD at age of majority.

Role of FASD in the lives of youth in care

Very few of the study participants had a thorough understanding of FASD as a disability. Seven of the youth acknowledged having been informed that they had FASD by a social worker or foster parents, but could not recall having an assessment done. Four youth were not sure if they had been diagnosed with FASD, while six stated that they did not have a formal diagnosis. Two youth were not even sure what FASD was. Those who had been diagnosed reported carrying a significant amount of shame about their disability and actively rejected the label due to their belief that others would expect less from them if they had FASD.

Despite the variations in their awareness of FASD, many youth expressed feelings of not being ‘normal’, a sense that they were different from others. They were quick to blame themselves when things did not work out in their lives, attributing their struggles to personal shortcomings. Placement breakdowns were especially internalized. The youth reported feeling argumentative, fatigued, anxious, frustrated, angry, aggressive, and destructive, and described experiences of being picked on, causing fights in the home, fighting at school, running away, being in trouble with the law, addictions, and mental health problems. Many of the struggles reported by these youth are characteristic of the secondary behaviours associated with FASD as described by Malbin (2004) and Streissguth et al. (2004).

Although the identification of ‘learning differently’ and not feeling ‘normal’ among the participants of this study was not attributed specifically to FASD, the perception of not feeling ‘normal’ was a source of considerable distress for these youth. Frequently, they expressed the desire to be like other people, who had life skills, jobs, and families, and succeeded in life. They were not always sure that these outcomes were possible for them, sometimes expecting that a program would teach them how to be ‘normal’ and comparing themselves to others for evidence that their achievements were approximating those goals.

Importance of relationships

The importance of relationships in the lives of the participants was a dominant theme in this study. Throughout their interviews, youth reflected on their desire for ‘real’ family connections. They acknowledged the limitations of their own biological families, many citing how family members were struggling with health concerns, substance addictions and other life challenges. Frequently, adolescents disclosed how much emotional pain the lack of relationship with biological family caused for them, describing this gap “like a hole”, suggesting a depth of unresolved grief and loss issues.

Even when contact with biological family did occur, the youth reported that it was often intermittent and unpredictable, and for the most part, they could not rely on biological family to be a support in their lives. For most of the youth, family relationships had been disrupted since early childhood, with 40% having entered care at the age of one year or younger, and another 45% entering care between the ages of 2 and 6, making the maintenance of relationships with biological families over the years a challenge. Instead, many adolescents seemed to direct their yearning for family connections to their foster families, quite understandably given the proportion of their lives spent in care. Although many youth had positive relationships with their foster parents, they still expressed their recognition that these relationships were created in a professional forum and were likely to terminate at age of majority. There was no guarantee that relationships would continue into adulthood, and some youth spoke poignantly about their lack of control over this facet of their lives (for example, “It’s hard knowing that they have the option of just shutting the door as soon as [you’re] 18, and it makes you feel like you don’t belong, because family is someone who cares for you and loves you”).

Additionally, some youth recounted that there had been no conversations between themselves and their foster families about whether continuing to live with them into adulthood was an option or what the nature of their contact might be after emancipation. There was great sensitivity around this issue for many youth, especially for those in long-term placements, one of whom worried that he might “become a burden” to his foster family for continuing to live with them into adulthood. For those youth who experienced disruptions in foster placement in later adolescence, relationships with foster parents may not have been long enough to even expect continuation into adulthood.

Some adolescents turned their feelings about not having family connections (whether foster family or biological family) to self-blame, identifying themselves as not worthy of relationships, as being difficult to live with, or difficult for others to care about. Others attributed family relationship problems to their behavioural choices and breaking the rules, which elicited the disapproval of others and, on occasion, placement breakdown. Few of the youth identified FASD as being a factor in these experiences.

The respondents also spoke about desiring stronger and closer relationships with their social workers, although they were cognizant of the professional nature of these relationships and that they shared their workers with other children in care. In particular, they wanted social workers to know them more intimately, their interests and needs, their strengths and weaknesses, and they wanted workers to be more genuine in their interactions with them. Much of their commentary about better relationships with workers was related to the professional context – involving youth in decisions about their lives and engaging them in planning for their futures – but with a degree of personal caring attached, perhaps to “keep in contact after they have transitioned, just to make sure they are okay”. At the same time, many youth shared that they had been assigned several different workers throughout their years in agency care, yet another example of relationship disruption in their lives.

Adolescent development for youth with FASD in care

The participants in this study identified ways that they tried to exert their independence throughout adolescence and the challenges they experienced. Most frequently, these challenges were related to their status of being a child in care and not attributed by the youth to having FASD. Many youth described difficulties that they had experienced when trying to follow the rules set by their agencies and foster parents. For these youth, the problem was not the rules themselves, but their inability to follow those rules. Other youth recounted instances of becoming so frustrated with the rules, especially when their desires were not being considered by foster parents or social workers, that they took matters into their own hands by running away or visiting siblings without permission. The limits to self-determination imposed by the child welfare system intensified the differences the youth in this study perceived between themselves and their peers who were not in care. They saw their peers as able to come and go as they pleased (within the general boundaries set by their parents), yet knew that this same freedom was not necessarily afforded to them by the child welfare system.

Many respondents experienced being in care as engendering dependence on others, as a result of being told what to do and suffering consequences for acting independently (especially if it involved breaking the rules). Several youth expressed their frustration with the control of the child welfare system, tension which often translated into strong statements about the participants' desire to leave the care and control of their child welfare agencies. For many participants, discharge from child welfare care simply meant more opportunity to make their own decisions. Other youth, comparing themselves to their peers, felt that they needed to be able to leave care in order to do the things that 'normal' people do. Although most youth in this study were provided with an extension of care, it is significant to note that two of the three youth who declined this opportunity did so expressly to be free from agency control. This outcome is particularly concerning, as having more time in care provides a valuable opportunity to develop the necessary skills and readiness for more successful transitioning at adulthood.

Many of the older respondents (age 18 – 21) in this study reflected back on their earlier adolescence, describing it as marked with "making mistakes" and "poor choices". But shifts in their perspectives were evident with growing maturity as youth reached age of majority or were already into early adulthood. This shift was evidenced in their descriptions of being ready for 'new beginnings', a sense of strength that had come from overcoming the past, and the identification of goals and ambitions. Older youth were also more cognizant of the challenges of independent living; although they looked forward to the opportunity, they also feared the responsibility and wondered who would help them if they had difficulty.

Younger youth (under 17 years) in the study presented an outward display of confidence that they would be able to manage independently at emancipation, citing "I can do it on my own" while also conceding there were many life skills they still needed to learn – an interesting contradiction. Future goals were non-specific; youth planned to "go day by day" and "see what happens". Their confidence might be interpreted as typical for this stage of development, when many adolescents are interested in emancipation from adult rules without fully appreciating the complexity of supporting one's self independently. However, even these younger adolescents knew that, unlike their peers who were not in care, they would need to act on their desire (and the necessity) for independence much earlier, but had developed no concrete strategies to navigate this transition.

Although older adolescents in this study were the only ones who demonstrated a capacity to reflect on the past and considered themselves to be at the threshold of a fresh start in their lives, all of the respondents expressed strong worries about the future and struggled with planning for the future and making their independent living plans a reality. Even many of those who were ready for ‘new beginnings’ did not have specific plans in place, and were not sure who might help them develop and implement any plans. A common reaction to looming independence was avoidance, with some youth admitting that thinking about the future created considerable anxiety.

Additional challenges during adolescence

In addition to the tasks of adolescent development, being a child in care, and living with FASD, six of the ten female respondents in this study also had children to raise. Although not all were necessarily parenting at the time of the study, all were intent on parenting as soon as they were deemed capable of doing so by their child welfare agencies. Some who had their children removed from their care stated that they had been advised by the agency that it was due to their developmental disability of having FASD, while others identified their poor behavioural choices as the reason they were not parenting at the time of the study.

Although more than half of the study participants had experienced disruptions in their education, they continued to identify high school graduation as an important indicator of success in life. Still, many found the traditional approach to education to be restrictive and they hoped to have more success at specialized school programs, while others reported difficulty in attending school consistently while also juggling the responsibilities of parenting. However, the main challenge identified by these youth was their different learning style which made it “hard to learn”, although FASD was not specified by youth as the reason behind their learning difficulties.

Experimentation with alcohol and drugs is not unusual in adolescence. However, some of the youth in this study attributed their involvement with substances as a by-product of reconnecting to biological family who still struggled with substance abuse issues themselves, while others provided the rationale that they had no other activities to occupy themselves. There was a degree of recognition that substance abuse was a concern and some participants had already taken steps to distance themselves from those who had substance abuse issues, whether biological family, partners, or peers. Others were no longer using substances presently, but acknowledged usage in the past.

Preparing for age of majority

Despite policies for Manitoba child welfare agencies guiding transitional planning for youth in care, the participants in this study revealed in their narratives a concerning disengagement from and lack of awareness of this process. Further, their stage of adolescent development and self-protective strategies predisposed them to casting a pretence of readiness for the challenges of adult autonomy, which in reality concealed their fears and their paucity of solid plans for the future. Of further concern, as reported by this study’s participants, extensions of care did not appear to enhance their involvement in actively planning for their futures.

Most youth could not recall having discussions with their social workers or their foster parents about what would happen to them at age of majority. Those who asked for help reported that they received little response. Many were planning to rely on themselves to figure things out, although their plans were vague, or they preferred not to think about the future and have just faith that things would work out. Younger youth were the least likely to be involved in specific planning for emancipation, but also expressed the most confidence in their ability to take care of themselves. Many youth were also confused about what transitional planning was even about, an indication that this process requires more leadership and transparency by the adults in their lives.

Perhaps one exception to transition planning that was initiated by caseworkers was the option to extend care beyond age of majority. In this study, almost all of the older adolescents had been offered (and accepted) the opportunity to extend care, usually to continue with school or to attend an independent living program.

However, extensions of care appeared to be offered “at the last minute”, very close to age of majority. Youth in care were not in a position to initiate these discussions, and either had to wait for transitional planning options to be raised with them or resign themselves to the need to plan on their own. The disconnections in relationships that these youth have experienced may play a significant role. As noted earlier, youth described feeling disconnected from their caseworkers, which makes it difficult for them to advocate for support in transitional planning (assuming they knew that such planning was important). It also appears that the youth were not sure if they had a strong enough relationship with their foster families to even broach the subject of continuing to live in the same foster home past age of majority, and reportedly, the adults in their lives were not raising the topic on their behalf, leaving them with fears about having to leave placement and agency care at age of majority.

Most respondents in this study described themselves as not involved in formal programming for independent living skill development. They were aware of the general types of skills they would need (for example, as related by one respondent, “how to cook, pay bills, and how to keep a steady job”), and recognized that they required assistance of some kind (usually identified as “programs”) to teach them the necessary skills. However, foster parents were cited as the most common source for assistance in developing independent living skills, although most youth in the study struggled to specify what skills they had mastered. Four youth were involved in independent living programs, but still struggled to articulate how these programs were helping them to develop specific skills they needed for successful emancipation. Often, the participants’ self-assessment of their independent living skills perpetuated the pattern observed in other aspects of this study: a veneer of confidence in one’s abilities, which served to conceal considerable gaps in substantive skills.

Although the participants in this study mainly did not identify FASD as a specific factor that interfered with their attainment of skills for independent living, older respondents had a more realistic appreciation of their skill strengths and deficits and commented on learning from past mistakes, suggesting a growing readiness to manage the responsibilities of emancipation over time. The findings from this study show that persons with FASD, much like their peers who are not affected, develop more capacity to think abstractly and to contemplate the cause and effect of their actions as they progress into young adulthood. However, only two youth identified FASD-specific services as something they would require in adulthood, an indication that better awareness of their disability and the availability of adult FASD services are needed.

Summary

In many respects, the findings from this study reflect what is reported in the literature concerning youth in care. The youth desire genuine relationships with people who will love them for who they are, not simply care for them because they are paid to do so. Yet their previous experiences – dysfunction in the family of origin, frequent moves, changes in foster parents and social workers, and the feeling that they are not in control of their own lives – have made it difficult for them to trust the adults in their lives, thereby hindering the development of meaningful relationships.

They have difficulty planning for the future, and although they are generally aware of the skills that they will need to live independently, they have been given little opportunity to practice those skills. However, they also exhibit a confidence in their abilities that belies their lack of skills and concrete plans for the future. Consequently, planning for the transition to adulthood is fraught with disengagement and rejection of potential supports, despite policies intended to ensure that youth are supported through emancipation.

The findings from this study are also consistent with the literature on youth with FASD in many ways.

The respondents reported having experienced difficulties in school, which frequently ended in school disruptions. The youth also exhibited secondary behaviours that are frequently associated with FASD, including anger, aggression, anxiety, poor self-concept, addictions, and mental health problems. Unfortunately, these youth don't have a good understanding of their disability and therefore blame themselves for the failures and disappointments in their lives.

Recommendations

FASD is a condition with significant and serious lifelong implications which are well documented in the professional literature. Comparable effects of FASD were evident in the lives of the youth who took part in this qualitative study. In conjunction with the impact of FASD, however, was the experience of growing up in child welfare care. An extensive body of research describes the adverse effects of long-term child welfare care on future outcomes, many of which had already been experienced by the participants of this study.

Yet, although they face formidable challenges, the adolescents in this study expressed determination to achieve the same characteristics of a positive life that seemed available to their peers who did not grow up in care: family, friends and meaningful work. Their spirit and resolution was striking and undiminished by the hardships they faced in life as they exited the child welfare system. Their fortitude should serve as inspiration, but our awareness of the very real barriers they face must remind us of the importance of providing FASD-affected youth with the services and supports they require to meet their goals as they transition into adulthood. Our challenge as practitioners, caregivers, policy-makers and researchers is to determine the most effective strategies to assist youth with FASD in child welfare care on their journey to adulthood, to mitigate both the impact of FASD and of growing up in alternate care on their lives.

The impact of FASD

The impact of FASD on the lives of youth in care can be ameliorated in several important ways. Canadian guidelines on the diagnosis of FASD are clear that professionals are obligated to ensure that all adults who work with a child with FASD (biological family, alternative caregivers, day care and school personnel, early intervention workers, etc.) should be informed of the diagnosis and assisted to develop strategies to best manage the impact of the condition on the child's functioning (Chudley et al., 2005). However, what may not be contemplated are the changes in membership in the child's support network that occur over time and how information is maintained and transferred among the support network members throughout these changes. Admissions to care and changes in caregivers, case managers and schools each may contribute to an erosion of information, leaving those who work most closely with a child uninformed about the exact nature and impact of the child's diagnosis. Further, children's capacity to understand their diagnosis changes as they mature; periodic discussions with the child to review how their condition affects their functioning at different stages of development helps to ensure that they have stronger self-awareness and positive coping skills.

Therefore, additional policies in the national guidelines are required to ensure that this information is regularly reviewed and updated throughout the child's life, to ensure that new members of the child's support network are well informed of the specific impact of FASD on that unique child's functioning. Preferably, each child should have a case manager identified within the FASD diagnostic team who retains an ongoing oversight responsibility for his/her FASD-related issues, such as periodic re-assessments of the child's functioning and coordination of team interventions to meet the child's changing needs.

The role of child welfare agencies merits specific mention in the national guidelines, given the central role that child welfare plays for so many children with FASD. Child welfare agencies are in a key position to manage the living arrangements, school enrollment, health care services and mental health supports of children with FASD who are in care. In particular, foster parents need to be identified as primary team members in supporting children with FASD. Strategies to ensure a strong linkage between the FASD service community and the child welfare system and its care providers, ideally through an FASD case manager as noted above, will be most helpful in this regard.

Reciprocally, the child welfare system needs to consider how the national guidelines impact its own standards of practice for children in care. Principles of the national guidelines point to the importance of early diagnosis, cultural sensitivity, and early intervention. Special focus on practice policies with regard to children with FASD are warranted, given the current proportion of children in care with FASD.

With FASD having life-long implications, expanding the range of adult FASD services becomes a priority. Data from the 2005 study by Fuchs, Burnside, Marchenski, and Mudry identified that up to 17% of all children in care in Manitoba had FASD, a figure that is considered to be a conservative estimate. Due to that research, a known and growing population of children with FASD will be approaching adulthood with considerable needs for services. The magnitude of those needs is underscored by the findings of this qualitative study. It is therefore an opportune time to begin development of a comprehensive range of support services for adults with FASD.

Relationships in the lives of youth with FASD

Like many children in care, the participants described their challenges in finding and maintaining supportive relationships with significant adults in their lives, experiencing great difficulty in this process which they often attributed to their own faults and failings. Biological family relationships are significantly disrupted when children come into care and may not be remediated during the course of the child's time in care. Those who did reconnect with biological family in adolescence or early adulthood often found family members still struggling with issues that prevented them from being reliable sources of support or guidance. While relationships with foster parents may be positive, the youth recognized that there were no guarantees that foster parents would love them and care for them the way biological families might be expected to do. These youth were acutely aware that their experience of living in foster care was markedly different from that of 'normal kids' who did not grow up in care. Consequently, they realized that they had to take responsibility for themselves at a much earlier age than their peers. Relationships with caseworkers were also identified as an important source of support.

Foster parents are indispensable supports in the life of a child in agency care. This study has demonstrated that children growing up in care from a young age direct their need for attachment to those who provide consistent care to them – their foster parents. Without opportunities to live with biological family, children in care seek bonding with their caregivers, yearning for genuine relationships, a real family, and a place to belong and call home. Uncertainty in relationships with caregivers may contribute to misbehaviour in adolescence, adding strain to the fostering relationship and increasing the risk of placement breakdown. Consequently, roles that all parents need to undertake in relation to adolescents, such as monitoring adolescent behaviour while also promoting age-appropriate independence, identifying and responding to risk indicators (such as signs of depression or substance use), assisting youth to develop greater responsibility in decision-making, role-modelling skills in conflict resolution, and advocating on behalf of the youth with external systems including schools (Small & Eastman, 1991), may not be fully employed by caregivers. This often leaves youth without the structure and guidance they need while navigating the challenges of adolescence.

It is critical, therefore, to develop alternative ways to ensure permanence for children in long-term care, subsequent to ascertaining a permanent placement. Specialized training for foster parents who are making a commitment to parent a permanent ward of a child welfare agency should address issues of role clarity, decision-making, transitional planning, and relational continuity. This will lead to foster parents having a stronger sense of their responsibilities and a stronger degree of sanctioned empowerment to engage in active decision-making on behalf of a child permanently in their care (VON, 2006). Permanent Ward Foster Parent Training will also need to focus on the many themes identified by the youth in this study, including attachment between the youth and the caregiver, the impact of child welfare care on adolescent development, methods to help adolescents acquire decision-making skills, techniques to assist youth with the development of independent living skills, and understanding the impact of disabilities such as FASD on child and adolescent functioning.

With stronger sanctioned status and affirmed commitment as a foster child's long-term parent, caregivers may be in a stronger position to take on the full range of roles and responsibilities otherwise expected of biological or adoptive parents. As relational permanence is established, foster parents may be more willing to preserve a relationship with a youth who presents with challenging behaviours in adolescence, a period that is often marked with placement breakdown. Additionally, foster parents can play a key intervention and advocacy role by engagement, involvement in community activities, and positive peer relationships. Their investment in the adolescent's life may yield considerable benefits for the youth, such as an enhanced ability to form trusting relationships, stability in the youth's support network, academic advancement, and a reduction in problematic behaviours, thus diminishing the risk of placement breakdown and promoting an environment in which youth can thrive and become better prepared for the responsibilities of adulthood.

Role of child welfare agencies

The importance of stability for youth in care cannot be over-emphasized; for youth with FASD, consistency is an essential element in managing the impact of the disability on functioning. Recent research suggests that the biggest issue facing foster children is not the fact that they are growing up in care (which often has protective benefits) but the impact of disruptions in their social networks when placements breakdown, youth move to new neighbourhoods and transition to new schools, leaving behind an established network of caregivers, foster siblings, peers, and community supports (Pecora et al., 2005; Perry, 2006). Given that disruptions to placement are more likely in early and middle adolescence, agencies should plan for their services to involve a good deal of crisis intervention, conflict resolution, strong advocacy, risk management, and relationship preservation. In short, any and all efforts should be employed to resolve crises that arise to maintain continuity of placement and school, as long as that continuity remains in the child's best interests. Partnering with foster parents in these endeavours is critical, given the daily contact caregivers have with their charges, but if placements break down, the agency and the social worker become the youth's main source of advocacy and support.

Despite proactive strategies to preserve foster home stability, placement breakdowns still may occur for a variety of reasons, and alternative strategies to maintaining relational bonds are necessary. One alternative described by Greeson, Usher, and Grinstein-Weiss (2010) is supporting the establishment of natural mentors for youth in care: a stable, caring adult who is already present in a youth's environment and who is willing to take on a committed role in assisting youth throughout life, including the transition into adulthood. Termed "one adult who is crazy about you" (p. 576), the authors demonstrated that natural mentors provide an opportunity for role modelling and social learning for youth in care, resulting in guidance and advice, emotional support, and practical help, and increasing the likelihood that the youth achieved concrete assets (e.g. bank account, vehicle) in adulthood. However, Perry (2006) cautions that if that one supportive relationship ends, the impact of that disruption of supports can be devastating for a vulnerable youth. Therefore, having multiple strong support networks is recommended.

Further, the relationship between the adolescent and the child welfare worker is critical. The youth who were involved in this study conveyed their desire to have closer relationships with their social workers, even though they acknowledged the professional origin of the relationship and the limited availability workers had, given their broader caseload responsibilities. In particular, the adolescents were looking for personalized qualities of the worker-client relationship, something that showed them that they were known as unique individuals by their workers. Strong connections between youth and their workers can be a powerful influence, using the basis of trust to negotiate compromise and facilitate stabilization in the midst of crisis.

Having close relationships with youth in care can contribute to a greater awareness of issues that may arise during adolescence, such as mental health concerns, substance abuse, sexual exploitation, gang involvement, or criminal activity. A key function of child welfare workers is supporting youth through their involvement with other systems when these issues surface, ensuring that the adolescent's needs are met and they receive the services they most require. Advocating on behalf of youth in care and coordinating services across systems, and with the foster home, are other important worker functions that are facilitated by a strong relationship between workers and youth in care.

Transition planning with adolescents

Another theme identified by the youth participants in this study was their disengagement from transition planning for future emancipation from child welfare. A number of youth-related factors may contribute to this phenomenon: their stage of adolescent development, their veneer of self-reliance, or the degree of crisis and disruption in their lives, for examples. Nonetheless, it is important to also consider how agency workers can improve youth engagement in transition planning.

Although standards of practice with regard to transitional planning for age of majority are well documented, many child welfare agencies in Manitoba do not consistently meet these expectations. Speculation as to why this occurs includes staff turnover, high caseloads, placement breakdown in adolescence, and unfamiliarity with the standards of practice. Regardless of the barriers, it is clear from this study that youth do not feel sufficiently involved in planning for their futures, and child welfare workers hold significant responsibility for addressing this.

Transitional planning with youth must include attention to the planned living arrangement at age of majority, eligibility for an extension of care, an assessment of independent living skills, referral to appropriate resources to develop life skills, and plans for education or vocational training. Some agencies offer their own set of support services to assist youth in developing independent living skills, while others rely on community-based programs. In general, though, there are not enough programs available for youth who need to prepare for emancipation, particularly in rural and northern regions of Manitoba, and none with a specialization in assisting youth with FASD.

Re-conceptualizing services for adolescents with FASD in care

It is clear that the participants in this study have confronted the same adverse risks of living with FASD and growing up in care as evidenced in the professional literature. While policies and programs exist to mitigate these risks and assist youth with the transition to adulthood, these efforts do not appear to be sufficiently meeting the needs of the participants in this study. The youth respondents spoke of not being engaged in transition planning and not knowing what specific skills they might require to manage the responsibilities of adulthood, but still portrayed a facade of self confidence that they could figure it out once they were on their own. Only the older respondents, already into their early twenties, showed an appreciation of the challenges they faced and acknowledged any degree of fear about how they would manage without the support of biological family, foster family, or their child welfare agency.

One of the most striking outcomes of this research is the clear progression of insight that developed as youth matured in early adulthood, leading to the assertion presented earlier that there is a significant mismatch between the timing of transitional planning activities/independent living preparation and the developmental readiness of youth in care. At age sixteen, when transitional planning is to begin, youth are still struggling with behavioural issues, school disruption, placement breakdowns, criminal justice involvement, experimentation with drugs and alcohol, and other well-known troubles of an adolescence spent in care. Child welfare workers may expend considerable energy responding to crisis issues experienced by the youth, leaving them little time to focus on transitional planning. But more importantly, at this stage the youth themselves are not able to focus on the future. Initiating transitional planning measures when youth are still in middle adolescence and not yet developmentally prepared to take full advantage of these processes proves to be a disservice to youth in care.

The timing of transitional planning is bound by the clock, stipulated by policy that endeavours to provide at least two years of preparation for emancipation before the youth exits care at age of majority. Only formal extensions of care for those youth who are willing and eligible provide any opportunity for matching developmental maturity with the provision of transitional planning services. However, the periods of extension provided to many of the respondents in this study tended to be a few months in duration, not long enough to reach a stage of more advanced maturity.

An obvious solution to address this mismatch is to ensure that more youth in care, especially those with FASD, are granted sufficiently long extensions of care to allow them to more thoroughly complete the developmental tasks of adolescence and become better prepared for emancipation. Once the crises of middle adolescence have stabilized and passed, youth are more capable of focusing on their future goals and applying the focus and energy required to build the skills and knowledge they will need in adulthood. In other words, extensions of care that continue into the young adult's early 20s have a better chance of matching transitional planning measures with developmental readiness.

However, this direction is not without its drawbacks. Extensions of care require the availability of caregivers, funding, case managers, and other agency resources to provide the kind of supports that these youth desperately need into early adulthood. Most jurisdictions struggle with high caseloads, limited foster care options, and financial constraints just providing adequate protection and care services to the children they already serve. Expanding the services of child welfare agencies into adulthood for an increasing proportion of vulnerable youth may strain the capacity of an already overburdened system to meet its mandate. While it can be argued that all youth who are permanent wards are vulnerable and likely in need of extended care, one alternative to managing the increased demands on the child welfare system may be to prioritize those youth who have FASD for extensions of care, viewing this disability as a compromising condition that merits special consideration.

More importantly, youth who are offered an extension of care are, for all legal purposes, adults. Extension of care that are merely a continuation of the same kinds of services provided to adolescents prior to age of majority do not adequately recognize the status of young adults receiving care. Although they can choose whether they want to accept extended care services from a child welfare agency, young adults in extended care do not have any choice in the kinds of services they will receive or the manner in which they will be provided. Failure to address this shift in status may keep young adults in an infantilized position, further perpetuating their feeling of being different from their peers. If the supports provided to them through extended care have the same features as the services received as children (characterized by the youth in this study as rigid rules, agency control, limited autonomy in decision-making, and risk of placement termination that is outside of their control), many youth will understandably refuse or tire of the constraints that go along with extensions of care. Further, providing services intended for children to an adult population perpetuates the mismatch between service provision and developmental need, even if those extended child welfare services include an emphasis on transitional planning and training in independent living skills.

An extensive reconceptualization of adolescence as experienced by youth in care is required, leading to the development of a robust range of services aimed at young adults who need additional support beyond age of majority to master the tasks of emancipation. While arguably beneficial for many youth who have grown up in care, the most vulnerable of the children-in-care population are adolescents with FASD, therefore this discussion will focus mainly on the needs of this focused population as they reach age of majority.

The literature reviewed for this study and the youth interviewed in our study indicated that at age of majority most youth have not yet attained the developmental readiness to live successfully on their own but are now at a stage where they can take advantage of services that prepare them for independent living. This would indicate that a program of transitional support services (including care) for young adults aged 18 – 21 is an ideal bridge between being a child in care and being a fully emancipated adult. In addition to age, criteria for eligibility in transitional support services would include being a permanent ward or a child who has been in care consistently since age 14, a diagnosis of FASD (to the extent that a diagnosis can be made under accepted diagnostic standards), and the consent of the young adult. Features of a robust transitional support services program for young adults with FASD at age of majority would include:

- negotiation of a transitional support services contract between the youth and the agency, including any additional supports such as alternative caregivers, community programs, educational/training programs, etc., outlining the nature of services being provided, the rights and responsibilities of the young adult in accepting services, and the roles that each party to the contract will play;
- development of a wide range of living options that approximate living on one's own, such as supported independent living, proctor arrangements, supported room and board, as well as foster homes and group homes that place heavy emphasis on the development of independent living skills, allowing youth more choice in where/how they will live as they make the transition to independence;
- wherever possible, the opportunity to continue in one's current foster home at age of majority, with redefined roles, rules and responsibilities of the youth and foster parent clearly articulated to provide youth with an appropriate balance between protection/ oversight and autonomy into adulthood;
- training for caregivers in the instruction of life skills, with special attention to adaptations required for teaching youth with FASD;
- development and evaluation of formal independent living skills programs for youth with FASD, including sufficient opportunity to practice skills frequently and receive feedback and guidance;
- the availability of youth mentors and life skills coaches to assist youth in the practical application of independent living skills and independent decision-making;
- vocational planning, including skills/interests assessment, training in employment-readiness skills (e.g. being on time, following directions, etc., including adaptations required as a result of the impact of FASD), job placements, and job coaching;
- the right of the young adult to leave the transitional services program at any time, but also to return to the program up to six months prior to reaching age 21.

Serious consideration should be given to the merits and disadvantages of offering transitional support services under the auspices of the child welfare system. There is no easy answer here: the opportunity to maintain child welfare placements while youth move through the latter stages of adolescence and transition to independence clearly supports investing transitional support services in child welfare agencies. However, the goal of normalizing transition and promoting adult independence favours a standalone program structure that supports residential care (whether foster placement, group home, or independent living) but exists separate from the child welfare system. Similar services currently exist through Manitoba's supports for adults with cognitive disability, although these youth generally do not meet the IQ disability criteria for these adult services.

While establishing a unique program of transitional support services for young adults leaving care may be the ideal goal, moving in that direction may take time that youth with FASD currently in care cannot afford. In the interim, legal provisions for extensions of care in child welfare legislation currently offer a mechanism for making services into adulthood possible for permanent wards with FASD who have reached age of majority. A defined extension of care program can be developed by creating a comprehensive cluster of transitional services and supports, accompanied by policies that articulate a different working relationship between young adults with FASD and the agencies that serve them, and between young adults with FASD and the caregivers who provide them with support.

Conclusion

This study demonstrates again the long term and significant personal and social impacts of prenatal exposure to alcohol. The challenges are felt broadly because of the number of children affected. They are also felt deeply due to the significance of their primary and secondary impacts on the life of each individual affected. Because many children with FASD are forced to rely on the child welfare system to provide safety and nurturing, social policy and practice must keep pace with their needs.

The adolescents and young adults with FASD, who shared their stories here, demonstrated both strength and courage as they moved through a child welfare system that struggled to address their needs first as children in care and then as children with a particular disability. Like other children leaving agency care, they experienced deficits in educational preparation, life skills, and social supports, elements that are critical to success as adults. In addition their disability created further barriers to acquiring the necessary education, life skills and social network.

This research suggests services to those with FASD could be improved at two intervention points. First, while children are in care, it is essential to increase a) the stability of their placements and b) their ability and that of their caregivers and service providers to recognize and manage the disability. Second, it is necessary to step away from a system that determines readiness for independence in a purely arbitrary fashion (i.e. “bound by the clock”) to establish a practice that would recognize the adaptive skills of the individual leaving care and plan for them according to their needs. Ideally that plan would recognize the adult status of those who reached the age of majority by increasing independence and choices without curtailing support or shutting the door on those who need more than one try at independence.

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Resilience and enculturation: Strengths among young offenders with Fetal Alcohol Spectrum Disorder

Billie Joe Rogers,¹ Kaitlyn McLachlan,² and Ronald Roesch²

¹ MA, Department of Psychology, Simon Fraser University, British Columbia, Canada

² PhD, Department of Psychology, Simon Fraser University, British Columbia, Canada

Corresponding author: Billie Joe Rogers, bjrogers@sfu.ca; 780-689-6246

Abstract

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong disorder with no cure and is accompanied by neurological deficits. FASD is a health concern that is increasingly gaining attention within the justice system. Research has identified an association between delinquency and prenatal alcohol exposure. This study looked at resources of resilience for young offenders and addressed questions regarding the association between enculturation and resilience, and whether offence histories differed between youth with and without a diagnosis of FASD. Ninety-four young offenders between 13 and 23 years of age participated, 47 diagnosed with FASD and 47 without. While this study was not intended to be a study on Aboriginal adolescence, given the overrepresentation of FASD among Aboriginal youth involved in justice settings, the Multigroup Ethnic Identity Measure (MEIM) was included to assess levels of enculturation among youth. The Child and Youth Resilience Measure (CYRM) was used to assess resilience. Results showed a positive association between the resilience-enhancing resources and enculturation, indicating that the two are intricately connected. Neither group differed in their rates on the resilience-enhancing resources or the enculturation measure. While the resilience measure was not significantly associated with official conviction data, it did demonstrate significant associations with self-reported offending data. Finally, no significant results emerged to suggest that FASD had an influence on the association between the resilience measure and offence history or the enculturation measure and offence history. Findings suggest the importance of incorporating cultural components into services targeted to produce resilience and positive outcomes, and that different groups may have different service needs.

Introduction

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term that consists of a range of behavioural, physical and cognitive deficits resulting from prenatal alcohol exposure (PAE; Chudley et al., 2005). Effects of FASD can include growth delays, dysmorphic facial features, and central nervous system (CNS)

impairments (Caley et al., 2005; Pacey, 2008). Effects of FASD are variable and can range in type, combination and severity depending on the frequency, amount and timing of alcohol consumption (Nicholson, 2008; Health Canada, 2003; Healthy Child Manitoba and Manitoba Education, Citizenship and Youth, 2009). A number of primary and secondary disabilities (adverse outcomes) are commonly associated with PAE. Primary disabilities are functional deficits that result from CNS injury (Streissguth et al., 1997). Neuropsychological domains of impairment for youth affected by FASD include executive functioning impairments, such as deficits in memory, understanding abstract concepts such as cause and effect, and decision making and planning (Nicholson, 2008). Furthermore, individuals affected by FASD may have poor judgment, engage in lying and stealing, and have little remorse for the consequences of their actions. Secondary disabilities can be understood as adverse outcomes that are prevalent in individuals with FASD. Streissguth et al. (1997) identified a number of adverse outcomes in their large scale study of adolescents and adults with the diagnosis: 90% experienced mental health problems; 60% experienced disrupted school; 60% experienced trouble with the law; 50% reported experiencing confinement, either in-patient treatment or incarceration for criminal behaviours; 50% exhibited inappropriate sexual behaviours; and 30% had experienced alcohol and/or drug problems (Streissguth et al. 1997).

Fetal Alcohol Spectrum Disorder and the justice system

FASD is a health concern that is increasingly gaining attention within the justice system. The intersection between FASD and the justice system is of interest because, as a result of associated primary and secondary disabilities, individuals affected by FASD can often experience difficulties within the justice system (Cunningham, Mishibinijima, Mohammed, Mountford, & Santiago, 2010). Of the possible diagnoses under the umbrella term FASD it is thought that the less visibly affected adolescents, who lack facial dysmorphological features, are more likely to exhibit delinquent behaviours. Fast, Conry, and Looch (1999) estimate that 60% of those with FASD have some sort of contact with the legal system and that of the youth remanded to forensic psychiatric facilities for inpatient assessments, 23.3% and 1% met criteria for FAS/FAE and full FAS respectively, suggesting a significant overrepresentation. When corrective measures are used on youth affected by FASD, it can result in frustration as oftentimes these individuals struggle with cause and effect (Healthy Child Manitoba and Manitoba Education, Citizenship and Youth, 2009).

Identity

Fetal Alcohol Spectrum Disorder, enculturation, and identity

Enculturation can be defined as the process by which ethnic individuals learn about their own ethnic culture, the extent to which they connect with that culture (Zimmerman & Ramirez-Valles, 1996), and is analogous to ethnic identity (Phinney, Chavira, & Tate, 1993). While there is variability in the construct of ethnic identity, there are also central components. The first component is self-identification, that is, a self-label that differentiates between self-identification (what ethnic identity an individual identifies with) and biological ethnicity. Affect is another central component, including feeling a sense of belonging, pride, and knowledge of the groups' history and traditions. Behaviours and practices are additional aspects; this refers to individualism versus collectivism, social activities, and cultural traditions (Phinney, 1992, 2000). Berry (1999) found that behavioural expression of identity was highest among Inuit and lowest among Métis, and adults demonstrated higher rates of identity compared to children and youth. Findings also showed that adults had stronger identities than children and adolescents. These findings are relevant because identity acquisition, whether social or ethnic identity, is an important part of adolescent development (Erikson, 1968; Kroger, 2003). In adolescence, youth are more concerned with how they are viewed by peers and fitting in with subculture rather than identity formation (Erikson, 1968; Larson & Richards, 1991). Identity acquisition in adolescence involves a process of exploration, which ultimately results in a commitment to identity (Roberts et al., 1999).

With respect to FASD and identity, it is important to discuss FASD in relation to Aboriginal² people in Canada, as studies have indicated increased prevalence in rural Aboriginal communities (Williams, Odaibo, & McGee, 1999). While this study was not intended to be a study on Aboriginal adolescence, there is a common misconception that FASD is an “ethnic problem,” in which those of Aboriginal ancestry are genetically at-risk for FASD (Chudley et al., 2005). Though First Nation communities are at high risk, it is not a genetically-based problem. Such comments do not consider the social determinants of health that increase the risk for Aboriginal populations (Tait, 2003) and do not include context such as colonization efforts and effects. The high risk for FASD among Aboriginal people can in part be attributed to colonization (i.e., residential school system, sixties scoop³) and its effects on subsequent generations (Tait, 2003). As Wemigwans (2005) notes, “Aboriginal communities are particularly sensitive to the stigma associated with FASD because it is not often contextualized as the product of a social problem but as a racial stereotype related to the evils of ‘Indians and Drinking’” (p. 9). Colonization of Aboriginal people has had dramatic and calamitous effects on Aboriginal families and communities. This is compounded by social determinants of health, including high rates of poverty and homelessness and low rates of education and employment contributing to substance abuse (Mitten, 2004).

Resilience

Of particular interest in the present study are factors that are associated with resilience and its relationship to offending patterns and histories. Rutter (1987) explains that resilience refers to the different ways in which individuals respond to risk. It is not a fixed attribute, but rather, the manner in which individuals respond to stress varies across time and situations. Ungar (2005a) explains that many understand resilience as something innate to the individual, a special intrinsic quality within the person that helps them overcome adversity. However, it is important to understand resilience as something more than an internal quality; understanding resilience should involve contextual, environmental, societal, and cultural aspects as well as relationships and opportunities that are available to individuals (Ungar, 2005a, b).

Theories of resilience

Across the literature, operational definitions of resilience appear to be inconsistent, though two prominent conceptualizations of resilience include resilience as a trait and resilience as a process. As a trait, resilience is best understood as those personal characteristics that allow for success in the face of adversity (Fougere & Daffern, 2011; Jacelon, 1997; Richardson, 2002). In terms of resilience as a trait, researchers have come to agreement on a triad of resilient traits, including personal characteristics such as easy temperament, family characteristics such as having a supportive family environment, and external supports such as positive role models (Fougere & Daffern, 2011). Though relative agreement on the triad

² The term Aboriginal is inclusive of First Nations, Inuit, and Métis peoples. These terms will be used interchangeably and will all be intentionally capitalized. This terminology will be used to define the first inhabitants in Canada, the United States, Australia and New Zealand. It is not the intention to group First Nations peoples into one homogenous group (van der Woerd & Cox, 2003).

³ The sixties scoop represents a period of time (1960-1970s) when large amounts of Aboriginal children (an estimated 20,000) were removed from their families and placed in the child welfare system and non-Aboriginal foster homes (Tait, 2003).

of resilience traits has been achieved, this level of agreement is not present when considering resilience as a process (Jacelon, 1997). On one hand, resilience as a process has been conceptualized as acquiring the triad of resilient traits (Richardson, 2002). Conversely, others have imposed a nested process on the triad in which protective processes exist within individual-level factors (traits), which in turn exists within the social-level factors (family support), and together they exist within societal-level factors (external support; Olsson, Bond, Burns, Vella-Brodrick, & Sawyer, 2003). The latter will be the theoretical framework that guided the present study.

Resilience and crime

A common limitation in research examining young offenders is a failure to examine strengths and protective factors. Resilience is one such protective factor that is thought to reduce the risk for crime and antisocial behavior (Rennie & Dolan, 2010). It has been argued that a continuum exists with resilience and vulnerability on opposing ends. When faced with adversity, people respond through a dynamic process, and depending on the response, they will end up at some point along the continuum (Jacelon, 1997). Youth labeled as at-risk, with delinquency limited to their adolescent years, show similarities to youth labeled as resilient (Fougere & Daffern, 2011; Ungar, 2001), suggesting that at-risk youth can still demonstrate resilience and the two constructs co-exist simultaneously at varying levels. Specifically, both groups may employ similar strategies in an effort to maintain their sense of well being (e.g., join a group), however, those who engage in antisocial behavior or crime will result in a deviant course through the system. Youth may gravitate towards delinquent peers and take part in delinquent behaviour as a way to fill a void or to acquire something that they need (Ungar, 2001). Echoing this view, Greene et al. (2003) note that health professionals believed that individuals would do whatever it takes to survive. For example, those who have unhealthy home environments may join gangs to gain a sense of belonging. In a gang, they have a sense of family; they are adapting to get what they need.

The present study

As part of a larger program of research examining the psycholegal abilities, risks, and needs of young offenders with FASD (McLachlan, in press), this study sought to target identifiable resilience aspects that could be used to develop intervention programs and inform the risk management literature. The overarching goal of this study aimed to move beyond psychopathologizing young offenders with FASD and towards a strength-based understanding of the association among resilience resources, enculturation and offending. Four research questions were asked, and hypotheses were subsequently tested. Research Question 1: What is the association between enculturation and resilience? Protective factors including traditions, ceremonies and the strength of one's ethnic identity are rooted in culture (O'Dougherty, Wright, & Masten, 2005). Given the intricate connection between resilience and culture, it was hypothesized that there would be a positive correlation between enculturation and resilience for each group in the study. Research Question 2: How do youth with and without FASD differ in terms of resilience and enculturation? Youth with FASD often come from marginalized communities and might feel very stigmatized due to the negative social connotations associated with this label and associated cognitive and behavioral challenges. It was hypothesized that individuals with FASD would endorse lower rates of resilience and enculturation. Research Question 3: Are specific areas of resilience components

(individual, caregivers, sense of belonging) associated with offence severity/history? While no hypotheses were formulated, interest in this question is rooted in previous literature, which theorizes a relationship between resilience and delinquent behaviours (Rennie & Dolan, 2010; Ungar, 2001). Research Question 4: Does the presence of FASD have a moderating effect on the association between offence history and resilience? Because some of the cognitive abilities (planning, impulse control) that have been identified as compromised or absent in individuals with FASD serve as resilience factors, it was hypothesized that the relationship between resilience resources and offending histories would function differently for youth with FASD, that is, the relationship would decrease for youth with FASD.

Method

Participants

Participants were 94 justice-involved adolescents between 13 and 23 years of age (77 male, 17 female). Forty-seven of the participants had a confirmed diagnosis of FASD based on Canadian diagnostic guidelines (Chudley et al., 2005). The remaining 47 participants served as the comparison group and did not have a diagnosis of FASD. Participants were recruited within the provinces of British Columbia (BC) and Manitoba. Recruitment of the FASD sample was conducted in collaboration with diagnostic programs with specialized referral streams for justice-involved youth. Recruitment of the comparison sample was done in collaboration with probation offices in the same jurisdictions from which the FASD sample was gathered. Recruitment of the comparison sample made efforts to match the samples on age, gender, and offence severity. Youth were excluded from the comparison group if there was suspicion of FASD or PAE.

Measures

The Multigroup Ethnic Identity Measure. The Revised (12-item) Multigroup Ethnic Identity Measure (MEIM; Roberts et al., 1999) was used to measure enculturation/ethnic identity. This 12-item measure is designed to assess enculturation and is based on Erickson's (1968) Developmental Theory and Tajfel and Turner's (1986) Social Identity Theory. A factor analysis of the MEIM yielded two factors; the first factor includes five items and is a developmental cognitive component termed ethnic identity search (EIS). The second factor, including seven items, is an affective component termed affirmation, belonging, and commitment (ABC). Psychometrics for this measure demonstrates adequate reliability (.81 in high school students and .90 in college students; Roberts et al., 1999). Cronbach's alpha in the current study was .94.

The Child and Youth Resilience Measure. The Child and Youth Resilience Measure (CYRM; Ungar et al., 2008) was used to measure characteristics and supports that enhance resilience. This 28-item measure is a culturally sensitive measure of resilience among youth. This measure focuses on individual, relationship-caregiver, and community-sense of belonging domains that reflect resilience. Psychometrics for this measure demonstrates adequate reliability (Ungar et al., 2008). Cronbach's alpha in the current study was .86.

Self Report of Offending. The Self Report of Offending (SRO) questionnaire (Huizinga, Esbensen, & Weiher, 1991) was used to measure offence history. The SRO collects information about self-reported offending behaviour throughout the lifetime. Information collected from the SRO may include offences that have not resulted in criminal convictions, and offences for which the individual has not been caught. The SRO includes aggressive, income related and public order offences. This questionnaire has good psychometric properties (Knight et al., 2004).

Procedure

Recruitment was undertaken in collaboration with service providers in the participating diagnostic clinics and probation offices. Service providers informed prospective participants about the study and provided researchers with the contact information of youth who expressed interest in participating. Active parental consent was obtained for all participants below the age of majority in each jurisdiction. All study procedures were consistent with ethical guidelines (Ethical Principles of Psychologists and Code of Conduct, 2002). Participants were met at diagnostic clinics, FASD justice programs, probation offices, detention facilities, and public libraries. As part of a larger study, participants were administered a battery of tests and an interview in addition to the three questionnaires in this study (MEIM, CYRM, SRO). Instructions were provided orally and youth were asked to be as honest as possible. The total interview was approximately three hours. Upon completion of the interview, tests, and questionnaires, participants were assessed for self-harm, debriefed and given \$25 gift cards for local attractions as compensation for their participation.

Results

Descriptive statistics

In order to deal with missing data, scores for missing items were imputed based on mean substitution of specific domains (Schafer & Graham, 2002). Seven participants failed to complete the CYRM entirely, leaving one or two items unanswered.

Descriptive statistics were calculated for both samples as well as for each predictor and dependent variable (see Table 1). Descriptive statistics showed that the majority of youth were male (81.9%), of Aboriginal heritage (71.3%, $n = 67$), and an average age of 17.5 ($SD = 1.61$). Of those who self-identified as Aboriginal, 59.7% ($n = 40$) indicated having Indian Status, 29.2% ($n = 20$) did not have Indian status, and 11.1% ($n = 7$) were unsure of their status. In terms of social demographics, 55.3% of the youth in this study were in custody at the time of being interviewed, and the remaining 44.7% were in the community. A total of 70.2% of the youth had prior or ongoing contact with child welfare services, with an average age of first placement beginning at 9.41 ($SD = 16.67$), and an average of 7.5 ($SD = 7.41$) placements. See Table 2 for group comparisons.

Table 1: Sample and Variable Descriptive Statistics

	All (n = 94)	FASD (n = 47)	Comparison (n = 47)
Sample	Mean (SD)	Mean (SD)	Mean (SD)
Age	17.50 (1.61)	17.53 (1.85)	17.47 (1.33)
	Frequency (%)	Frequency (%)	Frequency (%)
Gender			
Male	77 (81.9)	39 (83.0)	38 (80.9)
Female	17 (18.1)	8 (17.0)	9 (19.1)
Ethnicity			
Caucasian	17 (18.1)	6 (12.8)	11 (23.4)
Aboriginal	67 (71.3)	40 (85.1)	27 (57.4)
Asian	1 (1.1)	1 (2.1)	-
African	3 (1.1)	-	3 (6.4)
E.Indian	1 (3.2)	-	1 (2.1)
Other	5 (5.3)	-	5 (10.6)
Variable	Mean (SD)	Mean (SD)	Mean (SD)
MEIM	2.69 (.72)	2.60 (.76)	2.77 (.67)
<i>EIS</i>	2.39 (.78)	2.34 (.80)	2.44 (.76)
<i>ABC</i>	2.90 (.77)	2.78 (.81)	3.02 (.70)
CYRM	3.82 (.59)	3.75 (.65)	3.90 (.51)
<i>Individual</i>	4.07 (.58)	3.97 (.64)	4.18 (.50)
<i>Personal Skills</i>	4.15 (.65)	4.05 (.75)	4.25 (.53)
<i>Peer Support</i>	3.84 (1.02)	3.75 (1.01)	3.93 (1.03)
<i>Social Skills</i>	4.03 (.63)	3.92 (.70)	4.15 (.54)
<i>Relationship-Caregiving</i>	3.74 (.92)	3.67 (.98)	3.81 (.86)
<i>Physical</i>	3.60 (1.00)	3.53 (1.03)	3.66 (.97)
<i>Psychological</i>	3.80 (1.05)	3.73 (1.06)	3.87 (1.04)
<i>Context-Belonging</i>	3.61 (.76)	3.56 (.76)	3.66 (.76)
<i>Spiritual</i>	2.99 (1.20)	3.04 (1.18)	2.94 (1.20)
<i>Education</i>	3.69 (1.15)	3.68 (1.16)	3.69 (1.16)
<i>Cultural</i>	3.95 (.79)	3.83 (.88)	4.07 (.69)
LSRO	40.15 (19.43)	35.77 (18.17)	44.42 (19.86)
<i>Aggressive-related</i>	1.30 (.83)	1.13 (.76)	1.46 (.88)
<i>Income-related</i>	1.76 (.89)	1.55 (.86)	1.97 (.89)

EIS = Ethnic Identity Search; ABC = Affirmation, Belonging, Commitment

Table 2: Demographic Descriptive Statistics

Variable	FASD (<i>n</i> = 47)	Comparison (<i>n</i> = 47)
	Frequency (%)	Frequency (%)
Custody	25 (53.2)	27 (57.4)
Community Accommodation Prior to Custody	22 (46.8)	20 (42.6)
<i>Birth Parent(s)</i>	8 (30.8)	16 (55.1)
<i>Foster Home</i>	3 (11.5)	3 (10.3)
<i>Step Parent(s)</i>	-	2 (6.8)
<i>Adoptive Parents</i>	-	1 (3.4)
<i>Relative</i>	5 (19.2)	-
<i>Sibling</i>	-	1 (3.4)
<i>Independent</i>	1 (3.8)	3 (10.3)
<i>Group Home</i>	7 (26.9)	1 (3.4)
<i>No Fixed Address</i>	1 (3.8)	-
<i>Other</i>	1 (3.8)	1 (3.4)
Community Youth Accommodation		
<i>Birth Parent(s)</i>	6 (12.8)	10 (21.3)
<i>Foster Home</i>	8 (17)	3 (6.4)
<i>Step Parent(s)</i>	1 (2.1)	-
<i>Relative</i>	-	1 (2.1)
<i>Sibling</i>	-	1 (2.1)
<i>Independent</i>	3 (6.4)	4 (8.5)
<i>Group Home</i>	5 (10.6)	1 (2.1)
<i>No Fixed Address</i>	1 (2.1)	-
<i>Other</i>	-	1 (2.1)
Ever MCFD	43 (91.5)	23 (48.9)
Ever Homeless	15 (31.9)	14 (30.4)
Ever Custody	45 (95.7)	43 (93.5)
School Now	12 (25.5)	18 (38.3)
Ever Alt. School	41 (87.2)	33 (70.2)
	Mean (SD)	Mean (SD)
Age 1 st Apprehended to MCFD	5.05 (5.46)	17.57 (25.64)
# MCFD Placements	8.38 (7.89)	5.82 (6.23)
# Times Homeless	5.13 (6.47)	9.21 (25.60)
Age 1 st Homeless	13.73 (2.22)	20.36 (22.45)
Total Days in Custody (<i>lifetime</i>)	352.71 (382.35)	360.26 (279.02)
Last Grade Completed	8.55 (1.68)	8.87 (1.72)

Question 1: Association between resilience and enculturation

Given the intricate connection between resilience and culture, it was hypothesized that there would be a positive correlation between enculturation and resilience for each group in the study. Pearson product-moment correlation coefficients (Pearson's *r*) were computed to assess the association between resilience and enculturation. Consistent with predictions, a positive correlation was found between mean CYRM and MEIM scores for all youth in the study. For all youth in the study, enculturation was positively correlated with resilience, $r = .47, p < .001$, demonstrating a relationship between the components of resilience and enculturation.

Next, correlations between enculturation and resilience resources were assessed separately for each group in order to make comparisons. Positive correlations between the CYRM and MEIM total scores emerged for both the FASD group, $r = .49, p = .001$, and comparison group, $r = .41, p = .004$. As shown in Table 3, group differences emerged with respect to the associations between the CYRM’s individual domain, and relationship-caregiver domain and the MEIM’s ethnic identity search, and affirmation, belonging, and commitment factors. In the FASD group, the individual domain of the CYRM was significantly associated with enculturation (MEIM total score), $r = .31, p = .035$, in particular the ethnic identity search factor, $r = .34, p = .019$, but not with the affirmation, belonging, commitment factor, $r = .25, p = .087$. That is, youth affected by FASD who endorsed actively exploring their ethnic identity also indicated having individual level resilience (e.g., personal and social skills). However, the opposite was true for the comparison group as the individual domain was only significantly correlated with the affirmation, belonging, commitment factor, $r = .30, p = .038$. That is, youth in the comparison group who endorsed an affirmation and commitment to their ethnic identity also indicated higher individual levels of resilience. With respect to the relationship-caregiver CYRM domain, the FASD group showed significant correlations with the MEIM factors, while the comparison group did not. For instance, youth affected by FASD who endorsed both exploration and commitment to ethnic identity also endorsed resilience related to caregiver relationships (e.g., having physical and psychological caregiver support). Interestingly, both groups had significant associations with respect to the context-sense of belonging domain of the CYRM and the MEIM. That is, youth who endorsed an exploration of and affirmation of ethnic identity also endorsed increased levels of resilience related to a sense of belonging (e.g., spiritual and cultural supports).

Table 3: Correlations Among Predictors and Criterion Variables for All Youth

	FAS D	No FAS D	FAS D	No FAS D	FA S D	No FAS D	FAS D	No FAS D	FA S D	No FAS D	FAS D	No FAS D	
Variable	2.		2a.		2b.		3.		3a.		3b.		
1.CYRM Total Score	.487 [†]	.414 [†]	.460 [†]	.360*	.452 [†]	.402 [†]	-	.332 [°]	-.355*	-	-	-.232	-.400 [†]
<u>Individual</u>	.308 [°]	.265	.340 [°]	.170	.253	.303*	-.215	-.294*	-	-	-	-	-
Personal Skills	.197	.365*	.270	.304*	.124	.363*	-.219	-.288	-.29	-.307*	.095	-.249	-.235
Peer Support	.319 [°]	-.069	.242	-.206	.338 [°]	.046	.073	-.141	-.024	-.189	.134	-.148	-.148
Social Skills	.350 [°]	.243	.347 [°]	.139	.314 [°]	.291*	-.205	-.264	-.273	-.214	-.100	-.199	-.199
<u>Relation-Caregiver</u>	.356 [°]	.151	.309 [°]	.134	.350 [°]	.144	-.297	-.359*	-	-	-.154	-	-.488 [†]
Physical	.296 [°]	-.010	.261	.018	.28	-.031	-.059	-.146	-.254	-.332*	.043	-.237	-.237

					.9°				.028	.093		
Psychological	.342°	.179	.295°	.149	.338°	.178	-	-.359*	-.314°	-.350*	-.213	-.477†
<u>Context-Belonging</u>	.554†	.468†	.504†	.447†	.529†	.423†	-	-.182	-.300°	-.115	-.325°	-.184
Spiritual	.468†	.404†	.529†	.521†	.374†	.260	-.239	-.048	-.217	.048	-.273	-.103
Education	.050	.244	-.044	.163	.111	.275	-.246	-.280	-.260	-.217	-.165	-.207
Cultural	.554†	.451†	.469†	.336*	.554†	.480†	-.243	-.168	-.198	-.165	-.257	-.166
2.MEIM Total Score	1	1	-	-	-	-	-.121	.037	-.010	.025	-.161	.036
2a. <u>EIS</u>	-	-	1	1	-	-	-.137	.081	-.034	.096	-.206	.056
2b. <u>ABC</u>	-	-	-	-	1	1	-.097	-.002	.0909	-.033	-.111	.015
3.LSRO Total Score	-	-	-	-	-	-	1	1	-	-	-	-
3a. <u>Agg.</u>	-	-	-	-	-	-	-	-	1	1	-	-
3b. <u>Inc.</u>	-	-	-	-	-	-	-	-	-	-	1	1

† = Correlation significant at .01 level. ° = Correlation significant at .05 level
 EIS = Ethnic Identity Search; ABC = Affirmation, Belonging, Commitment
 LSRO = Lifetime Self-Reported Offences; Agg. = Aggression-Related Self Reported Offences; Inc. = Income-Related Self-Reported Offences

Question 2: Group differences of resilience and enculturation

Given the cognitive difficulties often associated with FASD (specifically insight as it relates to introspection), it was hypothesized that individuals with FASD would endorse lower rates of resilience and enculturation. Inconsistent with predictions, both groups demonstrated similarly high scores on both the CYRM and MEIM. Table 4 presents previously unpublished normative data for the CYRM in order to provide a benchmark for scores in the current study. The normative data is inclusive of both youth with complex needs and those identified as at lower risk. Youth at-risk and youth with poor social outcomes who were involved with two or more mandated services (e.g., mental health, justice) characterized the sample of youth with complex needs. Data from the current showed comparable mean and standard deviation scores to the normative data. An independent-samples t-test was conducted to compare

differences in resilience patterns between the FASD and comparison groups. No significant differences emerged in the scores for either group. This non-significant pattern was also true of enculturation between groups. Overall young offenders endorsed moderate rates of enculturation and resilience, demonstrating a connection with their ethnic identity and resilience at comparable rates.

Table 4: CYRM Normative and Project Data

Normative Data		Project Data	
	Mean (SD)		Mean (SD)
<i>All Youth</i> (n=2198)	108.60 (18.66)	<i>All</i> (n=94)	107.08 (16.38)
<i>Complex Needs Youth</i> (n=1071)	103.85 (20.18)	<i>FASD</i> (n=47)	104.92 (18.11)
<i>Low Risk Youth</i> (n=1128)	113.12 (15.82)	<i>Comparison</i> (n=47)	109.24 (14.32)

Question 3: Association between resilience and offence history

While no formal hypotheses were proposed with respect to potential associations between CYRM domains and offence history, it was thought that there would be an overall negative correlation between the total CYRM and offending. Pearson's r correlations were computed to assess the association between resilience and offence history. As shown in Table 3, significant negative correlations were found between lifetime self-reported offending behaviours (total score, income-related and aggressive-related scores) and resilience domains, suggesting the more youth reported characteristics and support related to resilience, the less they reported offending in their lifetime.

Resilience (CYRM total score) was negatively correlated with lifetime self-reported offending, $r = -.29$, $p = .006$, including both aggression-related, $r = -.28$, $p = .008$ and income related offences, $r = -.26$, $p = .012$. With respect to the association between domains of resilience and offence history, several group differences emerged. In the CYRM individual domain, no significant correlations emerged for the FASD group, however the comparison group showed significant correlations between the individual domain and lifetime self-reported offending, $r = -.29$, $p = .050$, specifically the aggression-related offences, $r = -.31$, $p = .038$. That is, youth in the comparison group who endorsed having higher levels of individual resilience (e.g., personal and social skills) also self reported less frequent rates of past aggressive offending. The same trend was evident in the FASD group, yet not at a level of statistical significance. These results suggest that for young offenders without FASD, higher self-reported levels of individual-level resilience, such as personal skills, were indicative of also reporting fewer previous offending behaviors. With respect to the CYRM relationship-caregiver domain, significant correlations emerged for the comparison group with respect to the association with lifetime self-reported offending, $r = -.36$, $p = .016$, aggression-related, $r = -.33$, $p = .024$, and income-related offences, $r = -.49$, $p = .001$, but not for the FASD group. That is, youth in the comparison group who endorsed having resilience relative to their caregiver relationships (e.g., having physical and psychological caregiver support) also self-reported engaging in less offending (both aggressive and income related offences). Youth affected by FASD who endorsed resilience relative to caregiver relationships demonstrated the same negative correlations, yet at a level of statistical significance. However, total lifetime self-reported offending was significantly correlated with

psychological caregiving for both the FASD group, $r = -.36, p = .017$, and the comparison group, $r = -.36, p = .015$. All youth in the study who indicated having resilience related to psychological caregiving (e.g., connection with and sense of safety from caregivers) reported less offending. Finally, with respect to the CYRM context-sense of belonging domain, no significant correlations emerged for the comparison group with self-reported offending, however the FASD group showed significant correlations between the context-sense of belonging domain and self-reported offending, $r = -.32, p = .027$, specifically aggression-related, $r = -.30, p = .048$, and income-related offences, $r = -.33, p = .027$. Youth affected by FASD who endorsed resilience related to a sense of belonging also self-reported less offending, while the same negative correlation for youth in the comparison group did not reach statistical significance. Overall, the relationship between resilience and enculturation seems to be more salient when it involves cultural and spiritual components for youth with FASD, whereas caregiving support and individual level characteristics in relation to enculturation appears more salient for youth without FASD.

Question 4: FASD as a moderator

It was hypothesized that the presence of FASD would moderate the association between resilience resources and offence history such that the relationship between resilience resources and offence history would function differently for youth with FASD, that is decrease this relationship. In order to examine this hypothesis, moderated regression analyses were conducted, in which, the criterion variables (lifetime self-reported offending and crime severity index) were regressed on the grouping variable (FASD versus comparison group), CYRM mean score, and the interaction between CYRM and the grouping variables. Results did not support the presence of a significant moderation between resilience and self-reported offending, $R^2 = .16, F(3,85) = 5.53, p = .002, \beta = -.19, p = .53$, suggesting that a diagnosis of FASD did not interact with the relationship between resilience and self-reported offending.

Discussion

A considerable amount of research on justice-involved youth is conducted with a psychopathologizing lens. The current study sought to target factors that influence resilience for justice-involved youth that can be later used in developing intervention programs.

Results from the present study indicated a positive association between resilience and overall ethnic identity for both the youth affected by FASD and those unaffected, such that youth who reported more resilience aspects also endorsed more cultural connection, belonging and overall ethnic identity. This association is consistent with literature noting an intricate connection between the two constructs; culture is embedded in resilience (O'Dougherty, Wright, & Masten, 2005). This association is particularly important because it speaks to the need for a focus on cultural aspects when building resilience capacity and positive outcomes. This association suggests two possibilities: first, those who have an increased sense of ethnic identity may seek out culturally relevant supports that work towards resilience. Second, those who access resilience-enhancing supports with cultural components (e.g., smudging) may gain a sense of ethnic identity in the process.

Examining differences in the association between enculturation and resilience among each group highlights the fact that youth affected by FASD may have differing needs and may require different foci within supports they receive. For instance, in terms of areas in which supports could focus, results specific to the FASD group suggest that youth exploring their ethnic identity may benefit from resilience enhancing supports that focus on the individual level (e.g., social skills), the psychological caregiving level (e.g., meaningful relationships with those who care for youth), and the sense of belonging level (e.g., spiritual and cultural aspects such as smudging or sweat lodges). On the other hand, youth affected by FASD who have already established their ethnic identity could benefit from efforts focusing on developing social skills (or other areas of individual resilience such as receiving peer support), receiving adequate physical and psychological caregiving, in addition to a focus on spiritual and cultural aspects. As can be seen in the literature, those with a diagnosis of FASD often have impaired social skills (Streissguth et al, 2004). Results specific to the comparison group suggest that both youth exploring their ethnic identity and youth who have already established their ethnic identity could benefit from supports that address individual level resilience factors (e.g., addressing anti-social attitudes), in addition to accessing supports that focus on spiritual and cultural components.

In this study neither group differed in their rates of resilience or enculturation, suggesting that when it comes to levels of self-identified ethnic identity and resilience, youth in this study held similar self-views. This finding was consistent with earlier, unpublished research indicating no differences between youth with complex needs and low risk youth. These results, in conjunction with the associations between resilience and enculturation previously mentioned suggest that while youth with FASD report resilience at the same rate as their non-affected counterparts, they may require different foci within resilience-enhancing supports.

Though no normative data on the enculturation measure (MEIM) was available for comparison, results from this study indicate that no significant differences were found between youth with and without FASD. A factor that may have contributed to the minimal differences in enculturation between groups could be that those of Caucasian ethnicity may not have thought about how their ethnicity affects them. Results from a study on identity found that individuals of African or mixed heritages valued racial ethnic identity in relation to self-concept more than Caucasians, while those of Caucasian descent indicated with higher frequencies that ethnic identity was not important at all to their self-concept (Jaret & Reitzes, 1999).

Furthermore, having a diagnosis of FASD did not differentially impact the relationship between resilience and rates of past offending, suggesting that youth with and without a diagnosis share the same relationship between resilience and offending behavior. This result makes sense in light of the lack of variability between groups in both areas. Though the two groups did differ significantly with respect to self-reported total offending rates, no significant differences were found when these were correlated with rates of resilience. These findings highlight the similarities that youth with and without FASD have in terms of the relationship between resilience and offending patterns. With respect to implications for intervention and supports designed for young offenders with FASD, such supports should focus on enhancing resilience.

In this study, resilience was significantly associated with lower rates of self-reported offending and these patterns differed between the two groups. With respect to reducing offending behaviours, results specific to the FASD group suggests that efforts should be made to enhance the youth's sense of spiritual and cultural belonging while enhancing caregiver support. For instance, participating in traditional activities, such as sweat lodges, and teachings from Elders, in addition to having healthy and nurturing caregivers may enhance cultural and spiritual connections, thereby serving as potential protective mechanisms through which youth may desist from offending. On the other hand, results specific to the comparison group speak to the possibility of a need for supports that enhance individual level factors (e.g., activities centered around mentorship programs). For instance, participating in activities that enhance personal social and vocational skills may enhance individual level competencies, thereby serving as a potential protective mechanism against offending. In spite of differences, both the FASD and comparison groups could benefit from caregiving ensuring psychological wellbeing as a mechanism to reduce offending behaviour. That is, youth who have healthy connections with their caregivers and feel psychologically and physically supported may decrease their offending behaviours. For instance, fostering parenting/caregiving skills can enhance educational outcomes and resilience among youth (Leve, Fisher, & Chamberlain, 2009). Overall, youth who were found to have more resilience also demonstrated lower rates of offending. This finding is particularly important as it speaks to the importance of building on strengths and resilience capacities within young offenders as a mechanism to produce positive outcomes.

Limitations

This research represents an important first step towards better understanding aspects of identity and resilience resources, however it was not without limitations. First, the use of self-report questionnaires may have introduced a source of inaccuracy, as it is possible that participants were dishonest or did not report accurately in efforts to demonstrate social desirability. Also, due to the cognitive deficits in areas including logic, reasoning, and insight, it is possible that youth with FASD had difficulty understanding the questions asked or lacked the insight to appropriately answer. However, comparable mean scores on several instruments provide evidence of the validity of these questionnaires in the FASD sample. Furthermore, limitations in logic and insight are also commonplace in adolescents owing to ongoing maturation and development of these skills (Beckman, 2004). A limitation of the MEIM is that some of the individuals who identified as "Caucasian" indicated they did not feel that the measure was relevant and had a hard time answering questions because they did not consider being Caucasian (often voiced as "white" or "Canadian" by participants) an ethnicity. In an attempt to develop a culturally relevant and sensitive measure, the authors of the tool (Roberts et al., 1999) may have overcompensated and made the measure irrelevant for Caucasian populations.

Future directions and implications

Though limitations exist, there are also strengths to this study. This is the first step in a program of research that will contribute to a body of research on FASD and adverse outcomes, such as involvement in the justice system. This research project may serve as a foundation upon which future research can build, and provides further impetus to focus on the importance of strength and resilience in marginalized populations. Future studies could examine the pathways of resilience and the process of being resilient to

further explore how resilience exists among young offenders. For instance, there is a need to understand how and when youth affected by FASD initially become involved in the justice system, in order to determine the critical “turning point” for this group of youth. Furthermore, determining how youth affected by FASD move between stages of delinquency and offending behaviours could provide useful information for interventions. Finally, understanding what is necessary to engage young offenders affected by FASD in programs that enhance resilience would be beneficial. Alternatively, research could examine other protective factors that may be unique to youth with FASD that were not examined in this particular study (e.g., consistency in support, cultural specific teachings). With respect to understanding protective factors and strengths of justice-involved youth affected by FASD, it would be beneficial to explore this from multiple points of view. That is, it would be beneficial to speak with youth themselves and ask them what they believe their strengths are and what they need to desist from offending. Other perspectives that could be sought include parents and/or primary caregivers, extending family and/or Elders, teachers, support workers, and service providers (e.g., youth probation officers and child welfare workers). Understanding the strengths and protective mechanisms of youth affected by FASD who are not justice-involved would provide useful information as to what aspects to enhance among justice-involved youth. An examination of family systems and dynamics in relation to offending could provide information useful for building strengths. That is, understanding how family dynamics and systems protect youth affected by FASD from offending could provide useful information for family interventions targeted at justice-involved youth affected by FASD. Finally, it would be beneficial to examine more thoroughly the association between the social determinants of health in Aboriginal populations and FASD; that is to focus on the issue of FASD solely within an Aboriginal sample, as this could provide context to the stigmatizing comments of FASD being an Aboriginal problem.

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Parents with Fetal Alcohol Spectrum Disorders in the child protection systems: Issues for parenting capacity assessments

Peter W. Choate¹

¹ PhD, RSW, Assistant Professor, Department of Social Work and Disability Studies, Mount Royal University, Alberta, Canada

Corresponding author: Peter W. Choate, pchoate@mtroyal.ca

Abstract

Parents who have or are thought to have Fetal Alcohol Spectrum Disorder (FASD) are often involved in the child protection systems, although there is little data to establish actual frequency. First Nations parents are over represented. There is often a presumptive bias that individuals with disabilities, including FASD, are not capable of raising their children. Such a bias is unwarranted. Assessing FASD parents requires a view of functional capacity along with consideration of how the parent could accomplish the role and if needed, with what supports. Both a context and process for Parenting Capacity Assessments (PCAs) in these cases is recommended. There is a need for the assessments to exist within a cultural context, including the use of the Medicine Wheel. The individualistic perspective of most Canadian child welfare systems may not match the collectivistic approach to parenting in an Aboriginal family system although it is from the former position that most PCAs are conducted.

Key words: Fetal Alcohol Spectrum Disorder, Parenting Capacity Assessments, Aboriginal parenting, parenting and child protection, FASD parents.

Introduction

Fetal Alcohol Spectrum Disorder (FASD) has long been recognized as a major concern for the development of children. Problems identified include behavioral, social and academic challenges along with self-regulation. There are often comorbid mental health issues such as Attention Deficit Hyperactivity Disorder, Oppositional Defiant Disorder, Conduct Disorder as well as Substance Abuse Disorders. As they transition to adulthood, they have a much higher risk of being involved in the criminal justice systems and face more challenges with employment. There is a large literature aimed at working with children who have been diagnosed or are suspected of having the disorder (Badry & Pelech, 2011; Bertrand, 2009; Blair, O'Connor, Frankel & Marquardt, 2006; Brown & Bedner, 2004; Ministry for Children and Families British Columbia (MCF), 1999; Rutman & Van Bibber, 2010).

These children are now becoming parents. The child protection systems (CPS) in Canada are facing the challenge of how to determine when these parents should be parenting their own children. FASD is a significant issue for CPS across Canada, although the actual rates are not well established. Indeed, the specific prevalence in the Canadian population, both Aboriginal and non-Aboriginal is poorly established (Pacey, 2010). Under diagnosis remains a substantial concern (Chudely, Conry, Cook, Looch, Rosales & LeBlanc, 2013). It is fairly well established that FASD is a significant concern with children in care and in Aboriginal populations (Tough, 2009). Pacey (2010) in a review of current knowledge indicates that diagnosed FASD children are more likely to be in institutional or foster care. Fuchs, Burnside, Marchenski & Murraray (2005) report on a Manitoba sample that 11% of all children in care and 34.2% of children with disabilities in care have been diagnosed with FASD. Fuchs, Burnside, Reinink & Marchenski (2010) indicate that there is surprisingly little known about how youth who have been in care and been diagnosed with FASD, fare as they transition to adulthood. Yet, they tend to come into care earlier, become permanent wards more quickly and will spend a greater amount of their life in care as compared to other children with disabilities (Fuchs, Burnside, Marchenski & Mudry, 2007).

However, under diagnosis remains a large problem meaning that many parents who have FASD have not been diagnosed. Thus, their parenting problems may well be seen as being something else, particularly a mental health concern (Malbin, 2004).

Virtually no attention has been paid to the question of how to assess parenting capacity of FASD parents who become involved with CPS. Social workers or the courts may order Parenting Capacity Assessments (PCA) with the goal of better understanding the strengths and limitations of the parent. The view is to determine whether the parent is going to be “good enough” to raise their child(ren). However, with this population, the question might be further framed, “Is this parent, along with appropriate supports, capable of being good enough to raise this child or be a significant presence in this child’s life?”

Aunos & Feldman (2007) note that parenting capacity consists of the combination of practical skills, which are directly related to parenting activity. But there are also parallel skills such as problem solving and personal management. An assessment must also look at the environment in which parents function, including their support systems. To be truly effective with this population, PCAs should be sensitive to the cultural context of the parent (Twiggg & Hengen, 2009).

The disability view – challenging it

Given the paucity of literature in respect of FASD parents, the next available database relates to parents with emotional, mental or physical disabilities. Researchers in those fields note that there is often a presumptive bias that such parents are quite unlikely to be able to successfully raise their children. As the research emerged, that bias has been found to be false. A large number of such parents are able to meet the needs of their children, although may often require supports. Booth & Booth (1998) found that some of the presumptive biases simply do not hold up to scrutiny, such as the belief that the children will become parentified. They also suggest that assessments are often deficit focused and should, instead, consider a resiliency approach.

When we use the FASD label to describe the parent, we flatten our understanding to that sole dimension. We make the labeling even worse when we stretch it to a First Nations person with FASD. This is a narrowing of the possible understanding of the person reinforcing the presumptive bias of inability as opposed to strength or resiliency. FASD is a spectrum disorder, which, by definition, means that the range of capacity will also exist across a spectrum.

In the same vein, it is wise to remember that First Nations cultures are no more homogenous than any other cultural group (Neckoway, Brownlee & Castellán, 2007, p. 70). . Thus, there is no “First Nations Formula” for PCAs. There is cultural sensitivity to the specific case before an assessor. Different parenting styles exist in different cultures and yield acceptable outcomes for the child (Phoenix & Husain, 2007). Different does not equate to not good enough.

Can interventions with FASD parents work?

In challenging the disability view, one also must accept that interventions can work with at least some of the FASD population. If they cannot, then assessment has reduced utility. The few studies that have been done, have shown that with appropriate intervention and supports, there is reason to believe that many FASD parents would be able to fulfill the requirements of the role (Denys, Rasmussen & Henneveld, 2011; Rasmussen Kully-Martnes, Denys, Badry, Henneveld, Wyper & Grant, 2010). This small literature base suggests that, as in the realm of disability research, there is reason to challenge the presumptive bias that FASD parents would, by definition, be unlikely up to the task.

Abraham (2005) demonstrated that supports for parents with FASD are often done by workers with little formal academic preparation in the area, although most had less formal training (p.71). This may impact outcomes. Needs for parents were identified around adaptive skills and those needed for daily living such as around housing, financial management and transportation (p. 79; see also Rutman & Van Bibber, 2010). With better preparation of support systems, such as seen in the disabilities sector, there may be a greater opportunities for FASD parents. In time, we may have a more thorough understanding of what will differentiate those who are more probable for success as opposed to those who are not.

An effective PCA can assist in identifying these differences. However, following Western approaches, which are concerning from a First Nations perspective, would not be wise. For example, the use of psychometrics faces a number of challenges with this population. To begin with, cognitive development and academic progress may make administration of these tools rather concerning with FASD individuals. Further, the author is unaware of any parenting measures that have norms established for FASD parents or the First Nations population. This makes their utility quite limited. As Bombay, Mathieson & Anisman (2009) show, most mental health measures are based on Western conceptualization of illness and are normalized against white, middle class samples (p.27). The same is largely true of parenting assessment measures.

Approaching the parenting capacity assessment

How then should an assessor approach the question of doing an effective PCA with a parent who has FASD or is suspected of having the disorder? The latter is crucial given that a significant number of people with FASD are not diagnosed (Chudley et al., 2013; Tough, 2009). Assessors should be sensitive to the possibility that the diagnosis might exist when they are presented with a parent having a profile or history consistent with possible FASD. The lack of openness by the assessor to this possibility will mean that a parent is being assessed with a significant void in the data.

There are several good formats for conducting PCAs (Budd, Clark & Connell, 2011; Choate, 2009; Pezzot-Pearce and Pearce, 2004). However, these again have been developed with a view to the broad, more Western population as opposed to either an FASD or Aboriginal parent. Stienhauer (1991) extols us to approach such assessment with a mind towards the least detrimental alternative.

Feldman & Aunos (2010) writing about disabled parents have strongly argued for a functional approach to assessment. The research tells us that FASD parents are likely to have cognitive and adaptive skill deficits (Malbin, 2004). This does not mean that they are absent of parenting skills. They may also have been victimized in their own formative years and lived with instability which can impact their understanding of healthy or at least, good enough parenting.

Many will have grown up in the care system. The state has often proven to not be a particularly good parent and thus, these parents may have maturational or life skill deficits that will be identified using a functional approach. A poignant example of the problems with growing up in the child protection system is seen in the 2005 presentation *Wards of the Crown* (Cazabon & Schnobb). It shows that the state may not be a better alternative to the parenting available through the parent with supports. Such negative experiences are not unique to Canada. Lemn Sissay (2012) has recently spoken about the challenges of growing up in care in the United Kingdom. Courtney et al., (2011, 2010) have shown that outcomes are poor for children growing up in care in the United States.

These experiences make it hard to engage parents in the assessment process. Such difficulty should not be interpreted as resistance but a natural impact of negative life events during formative years. Further, as Twigg & Hengen (2009) review, First Nations individuals find it hard to connect to traditional mental health approaches which is where most PCAs are rooted.

The core question – Can *this* parent raise *this* child?

The assessment should focus on the core question - can this parent raise this child (Pezzot-Pearce & Pearce, 2004)? In FASD cases, a second question might be added. Can this parent raise this child with supports? It does not need to be done alone. Such thinking is also consistent with the collectivist approach to Aboriginal parenting (Neckoway et al., 2007). It is also consistent with the disabilities literature (Feldman & Aunos, 2010). However, it raises the notion that assessment will need to look at the supports and not just the parent. The FASD parent who has the insight to recognize that they cannot do it alone, and needs supports, should be viewed as possessing a self-insightful strength. They may well be more willing to create a scaffold of support around them. The viability and utility of this is an important consideration that should be central to the assessment.

The label FASD does not inform about parenting capacity. Like many disabilities, FASD impacts exist on a spectrum ranging from rather mild through to quite significant. It is, therefore, the expression of the disorder that matters and how that impacts parenting. In cases where there is not a diagnosis, although it is suspected, a look at the functional capacity of the parent is more informative.

The assessment considers a variety of factors that will impinge on parenting. These can be thought of as including the parent's historical factors such as developmental history, trauma, education and employment, mental health and addictions and involvement in the child welfare system. Functional assessment would include decision-making, the nature of the relationship with and responsiveness to the child, the ability to manage self and the child, impulse control and financial management. When deficits are identified, consideration is required on the willingness to access and use both formal and informal supports.

The Medicine Wheel can be a useful tool given its cultural relevance and its ability to explore the areas just identified above for assessment. Using this tool, the Aboriginal parents (with or without FASD) may find inquiry of their life and parenting capacity more meaningful. It helps the parent to see how they may be living with their physical and mental health in or out of balance (Twigg & Hengen, 2009).

Parenting is bi-directional. The parent impacts the child and the child impacts the parent (Patterson & Fisher, 2002; Pettit & Ariswalla, 2008). Thus, the parent must be able to engage the child and permit ways for the child to engage the parent. When looking at direct behaviors of the parent with the child, the assessment considers the parent's ability to read the child's cues and to respond appropriately. Can the parent see the child at an appropriate developmental level? Can they provide a safe and nurturing environment? Can the parent help the child create meaningful relationships and experiences outside of the family? These might include kinship relationships as well as school, sports or other community activities. Can the parent support the child to acquire the skills needed to move through pre-adult developmental steps?

Risk is to be assessed. This includes poor impulse control that is connected to such things as crime, neglect of the child or other forms of maltreatment. Other risks include addictions, mental health as well as problems with self management including structures and routines that are beneficial to children. Grant, Ernst, Streissguth and Porter (1997) identify that the risks can be challenging, including poor judgment, failing to respond to the needs of the child and not appreciating those needs. Depending upon the nature of the risk, there may be worry arising from bringing into the child's life people who import risk into the family environment.

No PCA can be done without also considering the very unique needs of each child. As virtually anyone who has parented more than one child will tell you, each one is unique with specific needs. Some children are more demanding. There is the very real possibility that an FASD parent may have an FASD child. Thus, the needs of the child may be higher than might be experienced otherwise. Can the parent manage these specific needs (Pezzot-Pearce & Pearce, 2004)?

There is no window into the behavior of a parent that is better than seeing what happens in the actual interactions with the child. This requires time and should be done in as naturalistic environment as possible. Observations with parents who have FASD should be longer so as to observe a variety of parenting challenges and responses. Initially, the parent may be concerned about the assessor's presence, but this fades rather quickly in most cases. The point is to see how the parent operates at a functional level (Aunos & Feldman, 2007). As these authors note, the idea of seeing parents in action allows for a competency-based perspective that considers both the risk and protective factors (p. 227). Such an approach also balances the tendency towards a deficiency perspective that has been found to exist with assessment of parents with disabilities (Booth & Booth, 1998). These observations help to compare information from other sources with that which is happening in the actual observed interactions between parent and child.

Not about perfection

The standard that the assessment considers is whether or not the parenting can be good enough in the circumstances. The concept of a parent being good enough was found in the writing of British psychoanalyst Donald Winnicott (1957, 1964). His work raised the idea that perfectionism should not be the basis upon which a parent should be judged. Nor should parents strive to achieve this as it is unattainable. Something less was, in his view, ‘good enough’ to successfully raise a child. The concept again found favour in the work of Bruno Bettelheim in his highly readable parenting guide, *A Good Enough Parent* (1987). This was a self-help book on raising a child that reinforced the idea that much can be achieved in guiding a child towards adulthood without the parent being focused on perfection.

Parents raised either in foster or group care or in family situations where recovery from the traumas of the Residential Schools or the Sixties Scoop were an active part of the family story, may be less prepared for the role of parent (Mattens, Daily & Hodgson, 1998 as cited in Tait, 2003, p. 87). Generations of parent mentoring are missing. The question of “good enough” must consider that. How can that be managed and still create a “good enough” environment? It is with this perspective that assessment can minimize the risk of extending the oppression of the past into the present circumstances (Blackstock, 2009).

Tait (2003) has identified that there are a number of inter relating factors for mental distress and mental health that link to the impact of residential schools. FASD would be one such legacy. These legacies also impact parenting and family functioning through increased rates of physical and sexual abuse, suicide, mental health issues, family breakdowns and substance abuse and addiction (p.82). If the solutions are seen as removal of the children from the family system, then the intergenerational losses will be compounded and extended.

During both the residential school period and the Sixties Scoop (which went beyond that decade), Aboriginal mothers were deemed unfit to raise their children. Tait (2003) adds that this judgment was also applied to grandmothers looking after their grandchildren. Such an approach sees caregivers as independent actors with the children as opposed to seeing the nature of a collectivistic culture and the ability of the larger family system to care for children, such as can exist in Aboriginal communities. Child protection is typically focused on the primary caregiver although there are some efforts suggesting a broader view as recently published by one authority which says that they should give preference to kinship placements whenever possible (Calgary and Area Child and Family Services, (CFSA), 2013). PCAs should follow local legislation but also policy initiatives such as this that promote family, cultural and community connection. By focusing on sustaining connections, family systems can be supported and the loss of parenting skills from intergenerational traumas can begin the rebuilding process from within the culture (Bombay et al., 2009, p. 87).

As Tait (2003) notes, in the early twentieth century, physical health in Aboriginal communities was heavily impacted by epidemics. This was accompanied with poverty, inadequate nutrition, poor medical care and marginalization (p. 79). This too has impacted the parenting legacies compounding the effects of the residential schools. The Royal Commission on Aboriginal Peoples (RCAP) has clearly documented that these multiple adverse experiences have ongoing impacts on Aboriginal peoples throughout Canada and across generations (RCAP, 1996).

If an assessment does not take into account the present impact of these historical, collective intergenerational traumas, then it fails to fully understand the parent within their true environmental context.

It might also be worth framing Aboriginal parents with FASD as having the disorder layered on top of the intergenerational trauma. Fournier and Crey (1997) have articulated that, in the Sixties Scoop Aboriginal mothers were not measured on cultural determinants of acceptable parenting. Given that there continues to be a void in cultural specific elements to PCAs, this may be continuing.

When problems are identified with parenting capacity, the assessor must ask if they are treatable and / or manageable. The two are different. This might be illustrated this way. An addiction might be treatable through a rehabilitation program whereas a cognitive deficit might be managed through the use of external supports such as extended family involvement or a community support service. In FASD cases, both issues might be present – the need for treatment and management of varying issues. Treatment can be done with various physical and mental health resources while management is done with services through community agencies and extended family.

FASD parents arrive in child protection courts with what can often seem to be challenging histories and many obstacles to successful parenting. It is easy to overwhelm them. This can lead to giving up or a sense that it will never be possible to raise their own children. This can be further compounded if the recommendations arising from a PCA are numerous and onerous and do not reflect what might be treated or managed through resources that are, in particular, rooted within the Aboriginal communities and programs. To overwhelm an FASD parent is to set them up for failure.

Recommendations should take into consideration the motivation of the parent to succeed through learning and supports. In writing recommendations, a key question becomes what is possible within a reasonable period of time. What steps can be taken that will make a difference in parenting? Recommendations that focus on that, are practical, and can be implemented with resources available, will be the most useful.

An assessor, who takes into consideration solutions that may reflect not only the FASD but also the willingness of the extended family and the community to support the parent to meet the needs of the child, offers better hope for a child. Being raised inside the family system seems to offer a child better hope than being raised within the child protection system (Fuchs et al., 2010).

Conclusion

PCAs are an opportunity for an objective assessment of the capacity of a parent with FASD to determine if, and under what circumstances they could parent their child. These assessments are typically done when child protection is involved. Yet, if they are not methodologically sound, they can serve to harm rather than assist. If the parent is seen as incapable merely because of the FASD, or that becomes a part of the presumptive bias, then it will be hard for there to be a useful assessment in which all of the parties can have faith. It is hard for a parent to get an objective assessment if such bias exists.

FASD is a medical condition that is not well understood by many practitioners (Abraham, 2005). It might be argued that it is a specialized area. As Blackstock (2011) notes, many who work in child protection lack good training in key contextual areas that affect many FASD parents, being poverty reduction or substance misuse (p.36). It could well be argued that even fewer professionals working in and around child protection have specialized training in assessing FASD parents, partially because there is no significant training to be had in that area.

A review of the research that could be found on FASD individuals as parents is scarce and does not specifically address this need. Yet, it is well understood that PCAs are important and powerful features of child protection case management (Budd, Clark & Connell, 2011; Choate, 2009; Pezzot-Pearce & Pearce, 2004).

As Blackstock (2011, 2009, 2007) has suggested, child protection has a real risk of acting as a method by which oppressive practices continue with the Aboriginal peoples. A diagnosis of FASD places a person at increased risk given their vulnerabilities. To borrow Blackstock's term (2011), there is a need for "moral courage" to create an environment in which assessments are done from a depth of understanding that takes into consideration the diagnosis, the functional capacity of the parent, the needs of the child and the profound environmental issues arising from poverty, the history of oppression and its effects. When using an ecological and strengths based approach with FASD parents, a view of what is possible using the strengths of the parent and those who would support the parent. There can be a circle of positive attachment figures for a child that includes the FASD parent and other primary figures. This will spread the load and still provide a secure base for the child. Such thinking is consistent with an Aboriginal view of the role of family but runs counter to how child protection systems typically think of how parenting is to be done. In her presentation, Sims (2010) has shown that children can do well within a caregiving system.

Research has shown that children who grow up in the child protection systems remain at high risk for poor outcomes (Courtney et al., 2011; Courtney et al., 2010; Doyle, 2008). This should act as a modifier in thinking that children may be better off away from family. That might be true in cases where the risks cannot be managed. But this clearly suggests that such a consideration should be an essential element to these assessments.

A further consideration is that, if ways are not found to keep families intact within the Aboriginal communities, and children are removed from parental care because of FASD, then a further generation will be without parent mentoring from within their family system. This superimposes further intergenerational transmission of parenting deficits. A conscious and purposeful effort to reverse that trend requires that PCAs look at areas of strength that will allow FASD parents and their supports to raise the children. While it will not always be possible, seeing such a solution, as a natural option to be considered, is different than present PCA literature might suggest (Budd, Clark and Connell, 2011; Choate, 2009; Pezzot-Pearce and Pearce, 2004).

Area for future direction

It is apparent that the research base for looking at crucial issues around FASD parents is absent. There has been no review that the author is aware of that shows how FASD parents do over time; the quality of their parenting based on the severity of the disorder; no systemic view of best practices for assessment and no review of the ways in which FASD parents fare within the child protection systems. Thus, this review extrapolates the PCA literature in general and that which relates to other parents with disabilities.

Real efforts are needed to develop culturally sensitive approaches to assessing parents within the First Nations communities. The Medicine Wheel is one possibility although there is an absence of research that helps to know if this accurately identifies areas of strength and concern within parenting capacity. When combined with FASD, even less is known about culturally sensitive and effective mechanisms for assuring that useful, objective and accurate assessments are being conducted.

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An Interdisciplinary Journal

Honoring the Voices, Perspectives and Knowledges of First Peoples through Research, Critical Analyses, Stories, Standpoints and Media Reviews

Voices from the community: Developing effective community programs to support pregnant and early parenting women who use alcohol and other substances

Tasnim Nathoo,¹ Nancy Poole,² Margaret Bryans,³ Lynda Dechief,⁴ Samantha Hardeman,⁵ Lenora Marcellus,⁶ Elizabeth Poag,⁷ and Marliss Taylor⁸

¹ MSc, MSW, RSW, BC Centre of Excellence for Women's Health, Vancouver, British Columbia, Canada

² MA, Director, Research and Knowledge Translation, BC Centre of Excellence for Women's Health, Vancouver, British Columbia, Canada

³ RN, BN, Program Manager, Manito Ikwe Kagiiuwe, Mount Carmel Clinic, Winnipeg, Manitoba, Canada

⁴ MSc, Community-Based Researcher, Equality Consulting, Nelson, British Columbia, Canada

⁵ BScN, RN, H.E.R. Pregnancy Program, Streetworks, Edmonton, Alberta, Canada

⁶ RN, BSN, MN, PhD, Assistant Professor, School of Nursing, University of Victoria, British Columbia, Canada

⁷ RN, BSN, Public Health Nurse, Vancouver Island Health Authority, Victoria, British Columbia, Canada

⁸ BScN, RN, Program Manager, Streetworks, Edmonton, Alberta, Canada

Corresponding author: Tasnim Nathoo, groundedthoughts@gmail.com

Abstract

Since the 1990s, many communities in Canada have worked to develop specialized programs to meet the needs of pregnant and early parenting women who use alcohol and other substances. These programs provide a range of services under one roof (a "single-access" or "one-stop shop" model), address women's needs from a holistic perspective, provide practical and emotional support, and strive to reduce barriers to accessing care and support. Over the years, these programs have trialed new approaches to working with indigenous and non-indigenous women, their families, and their communities. In this paper, we describe the development of single-access programs in four different communities in Canada, discuss some of the elements of what makes these programs successful, and share our "lessons learned" over the years. We use examples from four different programs, including the Maxxine Wright Place Project in Surrey, BC; the Healthy, Empowered, Resilient (H.E.R) Pregnancy Program in Edmonton, AB; HerWay Home in Victoria, BC; and Manito Ikwe Kagiiuwe in Winnipeg, MB. All four programs are based upon the "best practices" elements of: (1) engagement and outreach, (2) harm reduction, (3) cultural safety (4) supporting mother and child, and (5) partnerships. In addition to serving First Nations, Métis, Inuit and other indigenous women and their families, these programs have drawn upon indigenous knowledge in their program design, values, and philosophy and have collaborated with indigenous women in evaluation and research to track the successes of these programs and to improve service delivery.

Introduction

Fetal Alcohol Spectrum Disorder (FASD) is a condition “unparalleled in its complexity” as a public health issue (Salmon, 2011). Although a key focus of federal FASD-related funding over the past two decades has been primary prevention campaigns, research strongly suggests that the women most likely to have a child with FASD are those who will be least likely be able to respond to awareness messages about the potential harms of consuming alcohol during pregnancy because of the overwhelming social conditions within which they live (BCCEWH, 2008; Poole, 2008).

In the early 1990s, several communities began to develop integrated responses to addressing the needs of pregnant and early parenting women with substance use issues. These early programs included *Sheway* in Vancouver’s Downtown Eastside and *Breaking the Cycle* in Toronto. These programs were designed to address the multiple barriers to accessing prenatal services that exist for many indigenous and non-indigenous women who use substances (Motz et al., 2006; Poole & Isaac, 2001; Poole, 2000; Racine, Motz, Leslie & Peplar, 2009). These barriers include fear of losing custody of children; fear of forced treatment or criminal prosecution; lack of treatment readiness; coexisting mental illness; guilt, denial and/or embarrassment regarding their substance use; previous negative experiences with health care and social service providers; and lack of transportation and/or child care. These programs were developed with an awareness of how substance use is often intertwined with other issues such as poverty, homelessness, gender-based violence, trauma, involvement with the law, loss of cultural and community connectedness, and food insecurity. These programs were considered innovative in that they trialed new approaches to addressing substance use and developed strategies to overcome system-level barriers to care such as negative attitudes of health care providers towards pregnant women who use substances and the traditional separation of prenatal care and substance use treatment and support within primarily a biomedical service model. In addition to serving First Nations, Métis, Inuit and other indigenous women and their families, these programs have drawn upon Indigenous knowledge in their program design, values, and philosophy; have collaborated with Indigenous women in evaluation and research to track the successes of these programs and to improve service delivery; and have been grounded in grassroots and activist movements to rebuild healthy indigenous communities.

Since the 1990s, other communities in Canada have learned from these pioneer programs and begun to develop specialized programs to meet the needs of pregnant and early parenting women who use alcohol and other substances. These newer programs have evolved within a context of greater awareness of issues like FASD, harm reduction approaches, cultural safety, and violence and trauma-informed care. The authors of this paper have been involved with developing, coordinating, and evaluating these programs for over 20 years. These programs include the Maxxine Wright Place Project in Surrey, BC; Healthy, Empowered, Resilient (H.E.R) Pregnancy Program in Edmonton, AB; HerWay Home in Victoria, BC; and Manito Ikwe Kagikwe in Winnipeg, MB. In this paper, we draw upon some of our experiences to describe the development of single-access programs in four different communities, discuss some of the elements of what makes these programs successful, and share our “lessons learned” over the years.

The single-access program model: An overview

While all four of the programs described below are different from each other in terms of funding, service delivery model, philosophies, and mandates, they share common elements that evaluation studies show work. Research evidence clearly shows that the single-access program model is an effective way of addressing the needs of pregnant and parenting women who use substances (Poole, 2006; Poole, 2008; Sword et al., 2009; United Nations Office on Drugs and Crime, 2008). Early engagement of pregnant women who use substances has been shown to positively affect a range of outcomes related to maternal, fetal, and child health and well-being (Cortis et al. 2009, Health Canada, 2006). Women who participate in these programs are more likely to keep custody of their child and have higher rates of accessing addictions treatment (Sword et al. 2009, Racine et al. 2009). Infants whose mothers have been supported during pregnancy demonstrate improved birth weight and reduced neonatal withdrawal effects (Marshall et al., 2005). Children who are involved with their mothers in a comprehensive early childhood program of support have demonstrated enhanced developmental outcomes (Motz et al., 2006).

All four programs started as unique networks of cross-sectoral partnerships that developed a common vision, values, and goals. The impetus for the programs varied in a number of ways. In one case, the program evolved from a meeting of concerned health care and social service providers. In another, it was a response to a specific community health crisis. Overall, people were observing the challenges that many women were facing and the poor outcomes for both mother and child, including high rates of child removal. All four programs provide a range of services under one roof (a “single-access” or “one-stop shop” model), address women’s needs from a holistic perspective, provide practical and emotional support, and strive to reduce barriers to accessing care and support. Each program also has developed unique strategies and innovations in program delivery. We briefly describe several “best practices” elements of the single-access program model below with examples from different programs and communities. The components described are: (1) engagement and outreach, (2) harm reduction, (3) cultural safety (4) supporting mother *and* child, and (5) partnerships.

Table 1: Examples of integrated community programs that support pregnant and parenting women who use substances across Canada

- HerWay Home, Victoria, BC
- Sheway, Vancouver, BC
- Maxxine Wright Place Project for High Risk Pregnant and Early Parenting Women, Surrey, BC
- H.E.R. (Healthy, Empowered, Resilient) Pregnancy Program (Streetworks Program), Edmonton, AB
- Manito Ikwe Kagiikwe (Spirit Woman Teachings), Winnipeg, MB
- New Choices, Hamilton, ON
- Breaking the Cycle, Toronto, ON

Engagement and outreach

When the Women in Shadows program started in Edmonton, AB in 2008, the program staff had to first figure out why so many women in inner city Edmonton were not accessing prenatal care. (The Women in Shadows program was a joint initiative between the Streetworks program and the STI Centre and ran from 2008-2010. This program was the foundation for the H.E.R. Pregnancy program, now based at Streetworks that started in 2011). They found that many women did not trust service providers, were ashamed of their substance use, or were frightened and hiding. For many First Nations, Inuit, and Metis women, this lack of trust was rooted in a history of residential schools and colonization and the intergenerational effects of this experience. For other women a history of trauma and violence, or past negative experiences with service providers were also factors. In response, the program hired two pregnancy support workers who had similar backgrounds as the women the program was trying to reach.

The two support workers worked closely with a nurse. They were trained in how to conduct some basic prenatal assessment skills, such as auscultating fetal heart rates, measuring fundal heights and maternal weights, and conducting kick counts. These skills were not used for diagnostic purposes. Instead, the support workers used them as a tool for engaging with pregnant women who were living on the streets. The outreach workers connected with women on the streets, built trusting relationships, and when women were ready, connected them to the program nurse and/or a physician in the community. In the first year, 78 women accessed the program and only one had an underweight baby.

Like the H.E.R. Pregnancy program, all single-access programs have been innovative in developing strategies to engage women. Outreach services have been a key component of all programs. Outreach services work with women where they are - on the streets, in their homes, in the hospital - and are not confined to providing services in one location. This provides service providers with flexibility in how they work with women. They can accompany women to appointments, share information informally, provide advocacy, and help overcome barriers like lack of transportation and distrust of formal settings.

Two of the programs, the Maxxine Wright Place Project in Surrey, BC and Manito Ikwe Kagiikwe in Winnipeg, MB started to provide outreach support to women while the rest of the program components were being developed. In Surrey, staff offered "wraparound" facilitation and support to women. The wraparound process is inherently responsive to women's need for collaborative support in response to challenging life circumstances. It works to coordinate and enhance a woman's existing supports and services and to develop an ongoing community of support and a plan of care tailored to her specific needs. The process "wraps" services "around" women rather than expecting them to conform to existing services (Cailleaux & Dechief, 2007). Providing outreach and wraparound support was a way for these organizations to strike a balance between meeting the immediate needs of women who were struggling with various issues now and developing a well thought out and multi-component program over a period of time. It also provided an opportunity to build relationships with other community partners and to demonstrate how a specialized program can make a difference in outcomes for women and their children.

Other strategies for engagement have included developing an intake process that involves minimal paper work and intake requirements and a program model where women could refer themselves to the program without requiring a formal referral from a physician or other service provider. All the programs have been developed so that women can choose which aspects of the program they are interested in and ready for. Initially, some women might be interested in accessing shelter or a hot meal; other women might be interested in seeing a nurse for prenatal care or talking with an addictions counsellor.

All of the programs have a strong emphasis on practical support. At Sheway and Maxxine Wright Place, the daily hot lunches have always been popular and one of the key reasons that many women attend the programs in the beginning - not only for the nutritional support but also for beginning to develop relationships and a sense of community. The single-access program model recognizes that without practical support, women cannot succeed in meeting other goals like reducing or stopping their substance use or learning parenting skills. Food vouchers, free prenatal vitamins, socks, bus tickets, and support in finding housing are just a few of the practical items that meet women's immediate needs.

Harm reduction

At HerWay Home in Victoria, BC, the program developers found that many of the women they were serving had previously had difficulties accessing the services they needed. Many women described having to travel around the city to attend multiple programs to get their needs met. Often, in this process, they described feeling vulnerable and judged negatively. One of the key goals in the development of HerWay Home was to bring together community partners (such as the regional health authority, pregnancy outreach programs, midwifery and nurse practitioner programs, mental health and addictions counselling, anti-violence services, parenting supports, and child welfare organizations) to create a collaborative "one stop shop" where women could access services in a respectful and non-judgmental environment.

The philosophy of harm reduction has been an important part of creating a respectful and non-judgmental environment (Boyd & Marcellus, 2007). Harm reduction recognizes that "success" does not always require abstinence from alcohol and drug use. A harm reduction approach means that abstinence is just one possible goal for women, and that care and support do not require women to address their substance use issues until they are ready. Harm reduction allows for flexible, respectful, and non-judgmental approaches to engaging with and caring for women and their children. It takes a "bird's eye" view of the issue of substance use by looking at a range of strategies to minimize drug-related harm to both the individual and society. Success might mean a woman reducing her substance use gradually throughout her pregnancy or building a relationship with an addictions counsellor that continues beyond the perinatal period. It might mean supporting a woman in leaving an abusive relationship and finding a new home and creating an environment in which stopping substance use is possible for her. It might mean focusing on other ways that a woman can take care of herself and her child other than quitting substance use, such as eating nutritious meals, attending regular medical appointments, and learning parenting skills.

While harm reduction is an effective method of working with women who use substances, it is not the only way of working with women. Many single-access programs collaborate with other organizations that have different philosophies and approaches, and even different understandings of problematic substance use (Benoit et al., in press). In some situations, this has created challenges in understanding how to best care for women and in fact may set up a tension between the approaches of women-focused and child-focused programs (Marcellus, 2004). With persistence, education, and a commitment to meeting the needs of women and their children, program staff have found ways to help other agencies and community stakeholders understand that women are best served when a continuum of options are available to them and that no one approach is better than another. Some of these discussions have highlighted how addictions issues remain poorly understood across society and how this is reflected in service delivery. There are also additional culturally based negative constructions of First Nations, Inuit and Metis women who are pregnant and experiencing addictions; Aboriginal women continue to be positioned as specific targets for FASD prevention (Salmon, 2011; Tait, 2000). In response, several programs have taken the initiative in providing training for health professionals on substance use and pregnancy. Others have had to overcome resource constraints such as there being only one physician in the community who can prescribe methadone, a drug used to support women with heroin and other opioid addictions.

Cultural safety

The development of the Maxxine Wright Place Project for High Risk Pregnant and Early Parenting Women in Surrey, BC was spearheaded by Atira Women's Resource Society, an anti-violence women's organization, in collaboration with representatives from Fraser Health, the Ministry of Child and Family Development, and ten other non-profit community agencies (Surrey High Risk Planning Committee, 2003). Atira Women's Resource Society provides a range of services for women ranging from housing and shelter programs to self-employment initiatives to 16 Step empowerment groups and outreach support. Because Atira is committed to supporting all women who are experiencing the impact of violence, the interconnections between gender-based violence and substance use has always been clearly elucidated in the program model. Maxxine Wright Place supports women who are pregnant (or who have very young children) who are also impacted by substance use and/or violence and abuse. Program statistics from 2007-2009 clearly show how these two areas overlap: 35% of women in the program had substance use issues; 14% had experienced violence/abuse in their lives; and 51% of the women experienced both substance use issues and violence/abuse in their relationships.

All of the single-access programs have found that substance use is often tied to women's experiences of violence and trauma. For many women, these experiences are linked to histories of colonization, residential schools, and migration. As a result, attention to issues of empowerment, trust and safety, cultural awareness, and social justice have shaped the development and success of these programs. At Maxxine Wright Place, this has meant offering specific programming for First Nations, Inuit, and Metis women, including outreach, a Re-Discover Parenting Program, and 16 Step Empowerment Group. When the program expanded and moved into a purpose-built three-story building, the clinic space was placed on the main floor and 12 units of emergency housing were built above. Women can access the shelter at any point during their pregnancy and potentially stay until their baby is 6 months old.

Other programs collaborate with Aboriginal organizations in a number of different ways ranging from program delivery on-site to involving women with first-hand experience of these issues in the development and evaluation of services to training health professionals in cultural awareness. Most of these programs are constantly reviewing and revising their approaches in response to emerging evidence on cultural safety and trauma-informed care. Cultural safety recognizes how a lack of trust and understanding between health care providers and patients and power imbalances can affect care and treatment and that the conditions that First Peoples experience today are a result of a history of colonization, residential schools, and other practices of cultural and social assimilation (Browne et al., 2009). Violence and trauma-informed care is committed to understanding the impact of trauma and violence on women's lives and takes this into account in all aspects of service delivery, with an emphasis on safety, choice, and control. While services are far from perfect, ongoing efforts to minimize re-traumatization and to create an environment in which issues of historical redress can be discussed are important to healing and support.

Many community-based perinatal programs also draw from the practice-based research conducted with First Nations women and treatment providers in Canadian addiction treatment programs (Acoose, Blunderfield, Dell, & Desjarlais, 2009). In a study that was concerned with how identity and stigma impact the healing journeys of Aboriginal women, the participants identified principles for culturally safe practice they wished treatment providers to embody: Recognition, Empathy, Communication, care, Link to spirituality, Acceptance, Inspiration, and Momentum (RECLAIM) (Dell, 2009, 2012a). These seven guiding values for practice are linked to the seven sacred teachings (respect, love, courage, wisdom, truth, humility and honesty) (Benton Banai, 1979; Dell, 2012b). Programs such as Manito Ikwe Kagiikwe find these holistic program values and traditional teachings a gentle and helpful approach to integrating cultural safety in their work. The combination of traditional approaches to care (holistic, community involvement, extended family, learning by doing, sharing circles, seven sacred teachings), ceremony, and a strong understanding of the impact of residential schools and colonization all interact to create a program that is culturally safe. Further, the program name "Manito Ikwe Kagiikwe" is an Ojibway word which means "Spirit Woman Teachings." This name refers to the idea that women carry all the teachings that they need within them and that the role of the program is to help women remember those teachings. Rather than attempting to "fix" or impose solutions on women, the philosophy of the program focuses on support and collaboration and relationship-building.

Honoring the experience, resilience and teachings of Aboriginal peoples, and especially Aboriginal women, has been the foundation for the development of meaningful services for Indigenous women. While many Aboriginal women who participate in these programs may not follow traditional practices or have different beliefs, using an Aboriginal worldview in program design and values appears to have benefits for women from diverse cultural/spiritual backgrounds.

Supporting mother and child

Often, when people think about women who use substances during pregnancy, there is overwhelming concern about potential harms to the fetus. However, this concern can often create barriers to care by viewing women's needs and children's needs as opposed to each other (Marcellus, 2004). Several of the single-access programs are finding ways to overcome this misconception by creating program models that view women's health and child health as inextricably linked. At Manito Ikwe Kagiikwe in Winnipeg, MB, the advisory group that worked to develop a model for the program considered these issues early in the development process. Manito Ikwe Kagiikwe, located at Mount Carmel Clinic, connected with the Anne Ross Day Nursery program which also runs out of the same organization. As the daycare program continues its own renewal and renovation process, Manito Ikwe Kagiikwe is co-evolving so that both programs will expand to include infants. As well, the advisory group decided that the program would support not only mothers whose children live with them, but also mothers whose children have been placed in care. All of the single-access programs avoid viewing a pregnant woman as "case" that requires assessment and management. Instead, staff attempt to work collaboratively with women, build partnerships with other service providers and agencies, and advocate for women to have a voice in their own support and care.

The single-access model views women's substance use outcomes, child development outcomes, and parenting outcomes as integrally linked. Many of these programs grew out of a recognition that high rates of child removal for women with substance use issues did not lead to success for either women or her children. The programs work to connect with women as early in pregnancy as possible so that relationships can be built and options can be explored. The programs have found that, with timely support, many women can successfully care for their children (Marshall et al., 2005) or safely make decisions to not continue with the pregnancy. Women can be supported in choosing other models of mothering such as part-time parenting, open adoption, kinship and elder support, and extended family. Some programs, such as Maxxine Wright Place and Manito Ikwe Kagiikwe, are integrated with daycare services. Other programs offer parenting support through a family support worker, parenting skills classes, or parenting drop-in. Several programs are providing support for women who are unable to care for their children or who choose to terminate their pregnancies and would benefit from support around grief and loss. This is an area of innovation as these are groups that historically have been overlooked in program delivery. In Victoria, BC, the Queen Alexandra Foundation for Children's Health, a children's philanthropic organization, recognized how mothers and babies' needs are linked and became a core fundraiser for HerWay Home. Gradually, individuals and organizations have been finding ways to overcome traditional barriers between adult services and child services and to look for solutions that benefit all.

Table 2: Examples of services and programs provided in a single-access model

- Pregnancy outreach workers
- Nursing support
- Family support worker
- Aboriginal outreach worker and/or cultural programming
- Drop-in program for pregnant women and new mothers
- Family doctors (including physicians who are able to prescribe methadone or have specialized training in addictions)
- Housing worker and/or supportive housing program
- Mental health and addictions counselling
- Early childhood development programming
- Availability of practical support, e.g., daily hot lunch, access to food bank hampers, provision of bus tickets and other help with transportation, free clothing, diapers and other baby items
- Advocacy and support in accessing additional services and programs

Partnerships

Studies have shown that women who use substances have difficulties accessing services that meet their needs. An integrated “one stop shop” model recognizes that no single service provider or agency can meet the often complex needs of women and that formal and non-traditional partnerships are required (e.g., between child-focused and adult-focused services). The single-access model requires innovative partnerships at all levels of service delivery and considers the needs of both mother and child.

One of the most important areas of collaboration has been with child welfare services. At Maxxine Wright Place (Surrey, BC), the social worker position was deliberately created to be “non-delegated” so that she did not have the authority to remove children. The program created a policy that child removals would not happen on-site, a policy that was essential to women feeling safe in accessing the program as a whole. It also created the opportunity for women to connect with child welfare services without the threat of their children being taken away and to build a relationship with a social worker so that solutions that worked for all parties involved could be explored. Thus, social workers are able to focus on women's immediate needs such as housing and income support and to begin to develop a longer-term care plan in collaboration with women. If child removals are likely or a possibility, women are involved in the removal process and receive support throughout and following the removal of the child by program staff.

At the H.E.R. Pregnancy Program (Edmonton, AB), one of the challenges the program has had to deal with is that, technically, Alberta Children & Youth Services cannot be involved with a fetus until the moment of birth. In the past, this has meant that women did not have an opportunity to learn about what they might need to have in place to be able to parent successfully. Working with a social worker located at the Boyle Street Community Services office, support workers have been able to connect pregnant women to a social worker prior to birth. The social worker has been able to act as a "consultant" so that women have a clearer understanding of what they might need to do to avoid having her child removed and to make plans to care for their child. It has also meant that women are able to have an opportunity to build a positive relationship with an individual in Children's Services and that social workers are able to learn more about individual women and their life circumstances apart from what their file might say. This earlier involvement with Children's Services has resulted in many more children going home with their mothers following birth. While the issue of supports and services during pregnancy technically do not fall within the mandate of child welfare services, the fact exists that vulnerable women with substance use problems do need such support services prior to giving birth.

Because all of these programs represent cross-sectoral partnerships, ongoing communication between involved parties has been critical. For example, HerWay Home has a community advisory council that includes representatives from the founding organizations (primarily women- and child-serving agencies) that work to ensure that the program remains true to the original philosophy over time. It also ensures that the program aligns with other community services so that duplicating or creating further gaps in service can be avoided. At the HerWay Home Program and Manito Ikwe Kagiikwe, "women's councils" comprised of women who have had personal experience with the issue of substance use while they were pregnant or new mothers are informing development of the programs.

Challenges and lessons learned

Single-access program models can lead to many successes for mothers and their children. However, there are always challenges in these programs and the complexity of issues such as multiple partnerships, governance models and funding structures for these programs can create obstacles and unforeseen difficulties (Bradshaw, 2007; Machold, Ahmed & Farquhar, 2007; Provan & Kenis, 2007). Flexibility in service delivery and in negotiating relationships is a requisite component of all these programs.

In many of these programs, there is an overwhelming demand for services and there have been challenges with providing adequate services with available staff and funding. For example, at Maxxine Wright Place, the program had to narrow its mandate by only accepting women who are pregnant or have a baby less than six months old and then providing services to women until their youngest child is four years old. Originally, women who had a child under two years of age were accepted and services were provided until the youngest child was six years old.

Many of our programs have been challenged in a number of areas such as shifts in funding and broader concerns of system fragmentation. This has meant that it is important to recognize the importance of working with available resources and building upon natural partnerships that already exist. Cross-sectoral partnerships have required all stakeholders involved to learn to work across different sectors, including community non-profit organizations, government, health care and with interested community members. Differences in values and priorities can sometimes create challenges in ensuring that all voices are equally valued and considered. Women with substance use issues offer a critical and compelling voice and this work represents a commitment to advocating for and ensuring that their experiences inform and shape program delivery.

Stigma and misconceptions about addictions and women who use substances while pregnant continue to create challenges. While attitudes are changing, there continues to be resistance to programs that use a harm reduction approach and a persistent view that women who use substances cannot care for their children. While there is already a strong body of evidence to support these programs, several programs have built partnerships with researchers and evaluators at local universities and with provincial and national research groups and centers so that national research funding can be accessed. This is one way that programs are seeking to build their profile in their communities and to contribute to the growing evidence based chronicling the success of these programs.

All of these emerging programs also have representation on the Canada FASD Research Network, in particular the network action team on FASD prevention from a woman's social determinants of health perspective. The benefits of the networking opportunities generated by this team have been immeasurable in contributing to this evidence base and in supporting community teams to move forward on developing these innovative programs. Recently, a research team has been focusing on developing principles and practices for evaluation of community-based prevention programs serving pregnant women and mothers. This evaluation framework includes an Aboriginal lens that helps to examine a range of outcomes: program philosophy, activities, formative outcomes, and participant, community, and systemic outcomes. This framework helps service providers in their local contexts remain aware of the interconnectedness of the range of factors that contribute to FASD in Aboriginal communities.

Acknowledgements

We acknowledge the financial support of the Canada FASD Research Network in the development of this paper.

Table 3: Online Resources

If you are interested in learning more about the philosophy, development, and outcomes of this type of program in other communities in Canada, the resources below are available for free and on-line.

Best Start. (2002). *Reducing the Impact: working with pregnant women who live in difficult life situations*. Toronto, ON: Best Start: Ontario's Maternal, Newborn and Early Child Development Resource Centre.

Download from <http://www.beststart.org>

FASD Network Action Team on FASD Prevention from a Women's Health Determinants Perspective. (2010). *10 Fundamental components of FASD prevention from a women's health determinants perspective*.

Download from <http://www.canfasd.ca>

FASD Network Action Team on FASD Prevention from a Women's Health Determinants Perspective. (2009). *Taking a relational approach: the importance of timely and supportive connections for women*.

Download from <http://www.canfasd.ca>

Leslie, M. (ed) (2007). *BTC Compendium, Vol. 1, The Roots of Relationship*. Toronto: The Mothercraft Press. http://www.mothercraft.ca/resource-library/publications/BTC_Compndium_2007.pdf.

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http://www.mothercraft.ca/resource-library/publications/BTC_JFAS_ReportFINAL.pdf.

Poole, N. (2000). *Evaluation Report of the Sheway Project for High-Risk, Pregnant and Parenting Women*. Vancouver: British Columbia Centre of Excellence for Women's Health.

<http://www.bcccewh.bc.ca/publications-resources/documents/shewayreport.pdf>.

Racine, N., Motz, M., Leslie, M. and Pepler, D. (2009). Breaking the Cycle Pregnancy Outreach Program: Reaching out to improve the health and well-being of pregnant substance involved mothers. *Journal of the Association for Research on Mothering*, 11 (1): 279-290. Download from

<http://pi.library.yorku.ca/ojs/index.php/jarm/article/view/22525/21005>

Streetworks Program website. Resources for clients and service providers, including the book *Oh Shit, I'm Pregnant: Your Guide to Being Pregnant on the Street*. Boyle Street Community Services, Edmonton, Alberta. Download from <http://www.streetworks.ca>

Surrey High Risk Pregnancy and Early Parenting Planning Committee. (2003). *Maxxine Wright Place Project For High Risk Pregnant And Early Parenting Women: Executive summary and Program Model*. Download from http://www.hss.gov.yk.ca/cnfp2010symposium/handouts_29/b2_am_maxx_wright_executive_summary.pdf

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<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2789048/>

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An Interdisciplinary Journal

Honoring the Voices, Perspectives and Knowledges of First Peoples through Research, Critical Analyses, Stories, Standpoints and Media Reviews

Voices of women living with FASD: Perspectives on promising approaches in substance use treatment, programs and care

Deborah Rutman¹

¹ PhD, School of Social Work, University of Victoria, Victoria, BC, Canada

Corresponding author: Deborah Rutman, drutman@uvic.ca

Abstract

Research and practice wisdom tells us that women who themselves have FASD are at high risk of having concurrent substance use and mental health problems, and of having a baby with FASD. Despite this, there is a dearth of published information that has focused on the support needs of women with FASD who have substance use problems, or on effective practice in providing substance use treatment and care for women with FASD.

This article presents findings based on interviews with 13 substance-using women with FASD, which was a key facet of a three-year research project that had three inter-related components. The research also included a review of the literature regarding promising approaches to substance use treatment and care with women with FASD and interviews with multi-disciplinary service providers across British Columbia to identify promising and innovative programs, resources and approaches relating to substance use treatment for women with FASD. Highlighted are promising approaches and good practice and/or programs for women with FASD who have addictions problems, from the perspective of individuals most directly affected by the issues: women with FASD who have substance use problems.

Keywords: *Fetal Alcohol Spectrum Disorder, FASD, FASD Prevention, substance use treatment for women, promising practices*

Introduction

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe a range of conditions and effects emerging from prenatal exposure to alcohol. FASD is a lifelong, invisible, physical disability with behavioural symptoms (Malbin, 2002). It gives rise to substantial physiological, cognitive, behavioural and social difficulties. Although the effects of FASD vary considerably there is tremendous heterogeneity in people's strengths and in the nature and degree of the harms and disabilities experienced by those living with FASD.

FASD is the leading known preventable cause of developmental disability in North America (Public Health Agency of Canada, 2005). Currently, the estimated prevalence rate of FASD in North America is 9.1 per 1000 live births (Motz, Leslie, Pepler, Moore & Freeman, 2006; Public Health Agency of Canada, 2005). At the same time, recent literature emphasizes the difficulties in obtaining accurate population-based prevalence rates. In particular, methodological flaws have been noted in prevalence studies involving certain populations, including Aboriginal peoples (Roberts & Associates, 2007).

In considering FASD within Aboriginal populations, Dell and Roberts (2006, 26) raise the issue that “Canadian studies on women’s use of alcohol during pregnancy, in particular in relation to FAS and FASD, disproportionately focus on Aboriginal women and the geographic areas in which they live”. Further, Tait (2003, 2009) and Hunting and Browne (2012) have noted that this disproportionate focus can result in heavily skewed data on the purported prevalence of FASD within both Aboriginal and non-Aboriginal populations. In fact, it has been demonstrated that there are very few epidemiological studies on the issue, and what data are available often are either high flawed methodologically or not disaggregated by sex (Pacey, 2009; Poole, Gelb & Trainor, 2008).

Rutman and Van Bibber (2010, 352) have emphasized the need to discuss FASD within its colonial context, and as well, within the context of (re)connecting to traditional knowledge and practices. They state:

In Aboriginal communities...FASD finds its roots in the colonial history of Canada. Colonization, racism and the deterioration of First Nation political and social institutions, the suppression of traditional spirituality, culture and language, the apprehension of children and loss of traditional lands and economies is the legacy of Canada’s settler history (Van Bibber, 1997). The residential school system proved extremely effective in destroying cultural pride and self-identity, in obliterating connections with traditional languages and in disrupting and severing family relationships (Tait, 2003). The current health and socio-economic conditions trace their beginnings to these historic events. What is less obvious when addressing issues such as FASD is the rich culture that existed before colonization, a culture so vibrant that its distinct nature lives on today.

In keeping with this, Dell, Acoose, and their colleagues, have spoken of the ways in which culture and cultural (re)connection are themselves healing ‘interventions’, and about the importance of ensuring that these ‘interventions’ are conceptualized and practiced within cultural contexts (see, for example, Dell et al, 2011; Dell & Acoose, 2008).

Currently, we do not have conclusive evidence regarding the likelihood that people who have FASD will have problematic substance use issues. However, the literature suggests that a disproportionate number of people with FASD will have substance use problems (Streissguth, Barr, Kogan & Bookstein, 1996). In addition, research has shown that women who have FASD are at high risk of having concurrent substance use, violence and trauma experiences, mental health problems, and of having a baby with FASD. Along these lines, one landmark study profiled 80 women who had children diagnosed with FASD. Of these 80 women: 100% had been abused; 90% had serious mental health issues, including Post Traumatic Stress Disorder; 80% lived with partners who did not want them to stop using substances; and approximately 50% had FAS conditions themselves (Astley, Bailey, Talbot & Clarren, 2000).

Given the reality that some women with FASD may also have substance use problems, combined with the likelihood that women with FASD are sexually active, it is not improbable that women with FASD may use alcohol or drugs while pregnant. Thus, from the perspective of FASD prevention, women with FASD need to be viewed as a group warranting particular attention.

Despite this, relatively little is known about women with FASD and their experiences in relation to substance use, in their attempts to access care related to their substance use, and in terms of what is good practice and promising substance use treatment programming for women with FASD. Without knowledge about good practice in working with women with FASD, it is very difficult to offer tailored and responsive services that provide effective prevention and treatment. Thus, it is critically important for practitioners, managers, program developers, policy makers, researchers, along with community support people to increase and apply knowledge about good practice in working with women who may have FASD.

To address this knowledge gap, the overall purpose of the *Substance-Using Women with FASD & FASD Prevention* project was to expand knowledge regarding effective, appropriate substance use treatment approaches for women living with Fetal Alcohol Spectrum Disorder. A key facet of our project was giving voice to substance using women with FASD regarding their views on ‘what works’ and what were the most helpful approaches employed within programs and by service providers, community resources and/or other support people (see Rutman, 2011b for the full report based on this component of the project). Additional components of this project were: a comprehensive review of the Canadian and international literature regarding promising practices in substance use treatment and care for women with FASD and semi-structured interviews with 40 multi-disciplinary service providers across British Columbia regarding innovative and promising programs, resources and approaches related to substance use treatment and care for women with FASD (see Gelb & Rutman, 2011, and Rutman, 2011a for reports based on these project components).

This article focusses on sharing the findings emerging from women’s perspectives in relation to promising approaches; as well, this article integrates these findings with the results arising from the other two components of our project. We conclude by sharing a wholistic framework for conceptualizing FASD effects and FASD-informed approaches that has emerged from our research and from subsequent interactive knowledge exchange events with Aboriginal and non-Aboriginal multi-disciplinary practitioners, program planners, policy makers, families, and people living with FASD. Indeed, in view of the far-reaching implications and applications of our findings and the emerging framework, we believe that this article has direct relevance for multiple and diverse audiences – practitioners, managers, policy makers, educators, researchers, community-based support people and advocates, and those living with FASD.

Research process

In keeping with research exploring people's lived experiences, the project employed a qualitative research design; as well, the research was informed by critical and participatory methods whereby those who had direct experience with the focal issues were centrally involved in the research process, as members of the project’s advisory committee, as project partners, and as part of the research team. A hallmark of these methodologies is the belief that participants' experiences and standpoints are the starting point and core of the inquiry (Barnsley & Ellis, 1992). These approaches also emphasize the importance of giving voice to those whose voices are often unheard.

For this component of the project, in-depth, face-to-face interviews were conducted with a total of 13 women with (suspected) FASD. In keeping with a number of qualitative methodologies, we employed theoretical (i.e., purposeful) sampling techniques whereby emphasis is placed on selecting appropriate, "information-rich cases" for in-depth study (Morse, 1994; Sandelowski, 1986). Research participants were both Aboriginal and non-Aboriginal women and came from four diverse communities in British Columbia.

Participants

Eligibility criteria for participation in the interviews were that participants were women who:

- had a substance use problem, or were birth mothers of a substance-exposed child, and
- self-reported having been prenatally exposed to alcohol or that their birth mother had alcohol use problems, or
- were assessed/diagnosed and/or self-identified as having FASD, or
- were raised by someone other than their birth parents and were identified by service providers or support people as having behaviours or characteristics in keeping with FASD.

Our project advisors – in particular, those who were staff of programs and organizations serving women with substance use problems – provided assistance in identifying a potential sample of interview participants. All women invited to participate in the project were current or former participants of community-based programs that were either specifically geared to people living with FASD or were for substance-using pregnant or parenting women.

In keeping with other studies focussing on issues for adults living with FASD, we did not require a diagnosis/assessment of FASD as a criterion for participation. This is because the majority of people living with FASD have not had a formal diagnosis. To ignore those who lack a diagnosis would be to further marginalize and dismiss the experiences of those living with FASD.

Nevertheless, during the course of our study, three women had received an FASD-related diagnosis (i.e., ARND; partial-FAS) following their involvement in an adult FASD diagnostic clinic, and all women either self-identified as having had been prenatally exposed to alcohol or identified with receiving services or care related to adults or families living with FASD.

The 13 women participating in the interviews ranged in age from their mid 20s to their early 50s. Four of the women (31%) identified as being of Aboriginal heritage, and nine women (69%) were Caucasian.

Interview process

The semi-structured interviews were carried out as guided conversations about people's lives and experiences. The interview guide was created in partnership with substance-using women and was pilot tested with two women who had been assessed as having FASD.

The interviews were open-ended and began with an invitation for the woman to tell their story or share anything about their history and/or current life circumstances, including their current living situation, their family and children, their involvement in raising their children, and their use of and/or difficulties with alcohol or drugs. The interview then focused on four primary questions: 1) What were women's positive experiences in substance use treatment and/or what had worked well for women in their experiences with services, and in particular with substance use treatment programs; 2) what hadn't worked well; 3) what would help improve substance use treatment programs; and 4) what were any other areas in the women's lives in which they needed help or support.

Interviews ranged from 30-90 minutes in duration and were carried out in a private location of the participant's choice. Interviews were either audiotaped with participants' consent, or extensive notes were taken, with every effort made to record participants' words verbatim. Participants were offered an honorarium in recognition of their time in taking part in an interview.

Findings

This article focuses on findings related to 'what works' and what are helpful and useful substance use-related programs, practices and approaches from the perspective of substance-using women with FASD. We begin, however, by sharing findings related to women's self-descriptions of themselves and their 'story', including their use of alcohol or drugs and how their substance use and FASD intersected with other areas of their lives.

Women's lives: Situating substance use and prenatal exposure to alcohol

Women as mothers

While each woman had a unique story, there were a number of important commonalities in their experiences. Foremost among these was that 12 of the 13 women were mothers, and their lives as mothers figured extremely prominently in their self-descriptions.

Beyond this common experience, however, there was variability; the number of children that each woman had and the children's ages varied considerably. Similarly, the children's health and their developmental and behavioural issues varied substantially. Although some women's children were "typical" from a neuro-developmental perspective, several women had at least one child who had an invisible disability such as FAS, FASD or Autism Spectrum Disorder.

Further, all 12 mothers had had some type of involvement with child welfare authorities, and all had had at least one child or children removed from their care for at least some period of time. At the same time, there was considerable variability in terms of whether the women had retained custody of one or more of their children and whether the women were in the midst of, or had been through, the process of attempting to regain custody of their child(ren).

Women as survivors of violence, trauma abuse, trauma, and related health issues

Nine of the 13 women participating in our study reported being survivors of violence, abuse and/or trauma in their childhood and/or adulthood. (It is important to note, however, that the women were not specifically asked whether they had these types of experiences. Thus, it is possible that other women experienced violence or trauma but did not volunteer this information as part of the interview. The women shared information relating to violence or abuse in response to an open-ended invitation to talk about themselves at the beginning of the interview and/or as part of talking about their needs in broad areas of their life.)

In addition, all of the women reported serious mental ill-health issues such as depression, anxiety and post-traumatic stress disorder, which they linked to the violence or abuse they experienced and/or to residential school experiences and related disconnection from culture, community and family. Further, several women spoke of experiencing feelings of intense anger and hopelessness following the removal of their children by child welfare authorities, as well as their feelings of shame or guilt related to having exposed their child(ren) prenatally to alcohol or other substances.

From a social determinants of health perspective, other key issues in the women's stories and self-descriptions were: their ongoing deep poverty; their difficulties in finding and keeping safe, affordable housing; challenges in accessing adequate child care; difficulties in finding employment; difficulties in maintaining healthy non-abusive relationships with their partners; difficulties in accessing mental health-related services and supports; and struggles with parenting, particularly if their child(ren) had a neuro-developmental disability.

Women as having Fetal Alcohol Spectrum Disorder

In terms of discussing having FASD, 10 of the 13 women shared information about their mother drinking heavily during pregnancy or generational substance use. Four of these women shared that they believed they had FASD. Nevertheless, none reported having been formally assessed or diagnosed with FASD. This is noteworthy given that, as stated in the Research Process section, three of the women had been involved in an adult FASD diagnosis clinic at the same time that they participated in the research interview for this project, and they had in fact received a diagnosis related to FASD. That these women did **not** disclose their having a diagnosis is indicative of one or more possibilities, including that their difficulties with memory and/or information processing interfered with their recollection or comprehension of the assessment results, they did not see the relevance of disclosing the assessment results in our interview, and/or they felt embarrassment, shame or a sense of stigma in relation to the assessment results and a diagnosis related to FASD.

Contextualizing women's substance use

Many of the women linked their problematic use of alcohol or drugs to their experiences of violence, abuse and trauma, their sense of hopelessness regarding their children's removal from their care, and their sense of disconnection from family, community and culture. One Aboriginal woman stated, "I wasn't prepared for that disconnect [from community]. It brought my soul down...and alcohol became heavier, and I started to lose my identity and family." This woman also linked her ongoing substance use to trauma related to residential school experiences: "Residential was part of that in my life also. I found out later, when I did treatment, that that was, at core, why the behaviour continued." Other important themes relating to the context of women's substance use were the influence of the woman's partner and the degree to which substance use appeared to the woman as being "normal" within her family or community. Along these lines, women also shared stories of how their partner's lack of support for their efforts to obtain services, or conversely, a partner's commitment to quitting made a pivotal difference in the success of their efforts to reduce their use.

In sum, what emerged from women's self-descriptions - even prior to their discussion of their experiences with substance use treatment and other programs and services - was their experience of multiple issues and struggles, of which their substance use (during pregnancy) was only one. The women did not compartmentalize their substance use (or any other single issue in their lives), and thus, substance use programming must see the whole woman and place women's substance use within the context of their lives and day-to-day realities.

What works – Women's positive experiences in receiving services

A number of themes emerged in response to the question of what had been helpful in women's experiences with programs and services, and what 'worked' in assisting them to quit or reduce their problem alcohol or drug use. These themes included both helpful approaches and aspects of the support received from a service provider, family member or partner, and identification of particular programs or resources that were reported to be especially effective.

The themes in women's discussion included:

- Women's readiness for change is crucial; thus, working with women "where they are at" is vitally important
- A relationship-based, culturally safe approach is key
- Wholistic and integrated programs are most useful
- One-to-one support from a skilled professional combined with women-centred, peer-based support is most effective
- Flexibility in extending the program's duration is helpful
- Service providers being knowledgeable about FASD is essential

It is important to note that a number of the programs reported by women to have been helpful were not actual substance use treatment programs. Instead, they were personal development, employability or mothering-mentorship programs guided by a wholistic framework that recognized that women seeking support often had multiple issues that needed to be addressed in an integrated way. Additional discussion of the first three of the above themes follows.

Readiness for change

Nearly all of the women interviewed emphasized the importance of being ready to make a change in their life and in relation to their substance use. Indeed, from women's perspective, their genuine readiness for change was what distinguished their successful experience of reducing or quitting their problematic substance use from other experiences or instances when they tried to quit or entered treatment programs but in fact were not ready. One woman thus noted that "being ready" trumped court-ordered programs if readiness was not present: "For myself, I feel that you have to be ready. You have to be ready, and if you're not ready for it, it's a waste of people's time and your time. Because you just get to the point where you need to do something. Court orders just don't do it." Another woman similarly stated, "Getting the help was easy – staying clean was hard. When I was ready, the help was there."

Further, for the majority of women taking part in our interviews, readiness for change and for reducing or quitting alcohol or drug use was related to either their pregnancy or their efforts to regain care or custody of their child(ren). Indeed, for some, pregnancy and desire for their baby's good health triggered their recognition that they were ready to quit using alcohol or other substances. In one woman's words, "I wasn't ready at the beginning. Then found out I was pregnant, and I knew I was ready."

Relational, culturally safe approach

All women interviewed spoke clearly and emphatically about this point: "what works" and what was foundational to their positive experiences in programs was their having a trusting, honest, respectful and caring relationship with a service provider or support person, wherein they felt safe and did not feel judged, blamed or shamed.

"[The mentoring program] was unique. Women came because they felt safe. We learned so much and felt so safe. These women learned to trust and it was fantastic."

"They didn't shame me at the Centre. Took me through my history and helped me to understand why. Try to build your self-esteem along the way."

Service providers' understanding of the complexity of the issues and practical support needs facing substance-using women and women living with FASD was also clearly valued by women.

I had support from Metis Services. A man who worked there was awesome. He really cared about me. A child care social worker was also very helpful – he really understood FAS.I don't think I would be nearly where I'm at if it wasn't for them. They genuinely cared; they had a lot of knowledge, compassion and personal experience.

Along similar lines, women expressed deep appreciation for service providers who conveyed their confidence in the women's ability to make changes in their life and who didn't "give up" on them, even if they had setbacks that impeded their progress in achieving their goals.

He had faith in me. I kept screwing up, but he kept supporting me. Even though he was tough, I have a lot of respect for him.

Wholistic and integrated programs

As discussed in the preceding section, the women interviewed for this study did not compartmentalize their substance use problems and related needs for services or support as being unrelated to the other areas in their life in which they needed assistance. Thus, from their perspective, 'what worked' best were multi-faceted participant-centred programs that approached women's lives and needs wholistically, as well as programs that were well coordinated or integrated with other services or resources serving women.

For example, several of the women participating in interviews had been involved with, and were extremely positive about, a mothering-focused program that, in addition to offering peer mentoring related to mothering, also offered one-to-one support from a skilled counsellor who assisted women with their individual issues in the areas of housing, tenancy, financial literacy, employment-readiness, and life skills, and safety in relationships. As one woman stated:

Support, support, support from non-government people who understand how important practical support is. Getting a phone bill paid, a grocery voucher, daycare so we can go to meetings. Help in raising FASD kids – or any kids – having FASD is tough – my house is filthy – I don't know how to clean – I barely get my kids to school. [The program facilitator] used to get me a housekeeper and someone to help me manage my life.

As indicated by this comment, and underscoring a point discussed above, along with women's appreciation of programs that were wholistic and flexible was their valuing of programs and program staff that had a strong understanding of FASD and the needs of children and adults living with FASD.

Discussion

The findings presented in this article were based on community-based interviews with four Aboriginal and nine non-Aboriginal substance-using women who had or were suspected of having FASD; the study was not limited to Aboriginal women with (suspected) FASD. These interviews comprised one of the three components of the *Substance-Using Women with FASD and FASD Prevention* project. The other two components were interviews with 40 multi-disciplinary service providers working with women with substance use problems or at risk of having a baby with FASD, and a comprehensive literature review aimed at identifying promising approaches to substance use treatment and care for women with FASD.

In our qualitative interviews, women were able to share their story in their own words. At the same time, the interviews largely focused on: women's positive experiences in substance use treatment and/or other types of programming and/or what they believed had been helpful in relation to dealing with their problem alcohol or drug use; what hadn't worked well; and what, based on their experience, would help improve substance use treatment programs and care.

While women's stories and experiences were as varied as the women themselves, emerging at the core of their self-descriptions were several common, inter-connected themes, including: being mothers; being survivors of abuse and trauma, and living in highly fragile domestic relationships in which they were vulnerable physically, emotionally and/or financially; having mental health issues and needs related to their experiences of abuse and trauma; struggling to find stable, safe housing for themselves and their children; living in deep poverty and continually struggling to find ways to make ends meet; being entangled with and at times feeling vulnerable or vigilant in relation to the child welfare system; and having problem substance use which typically exacerbated their involvement with child welfare authorities. Notably, having FASD was not generally a key aspect of women's descriptions of themselves.

Also notably, the life experiences and self-descriptions of the women in our study paralleled those reported elsewhere in the literature, including in key research on characteristics of biological mothers of children with FASD (e.g., Badry, 2008). For example, one landmark study found that of the 80 birth mothers whose children were undergoing assessment for FASD, nearly 100% were survivors of physical or sexual abuse and had serious mental health issues, and roughly 50% of these women reported being prenatally exposed to alcohol themselves (Astley et al, 2000).

The women's self-descriptions are an important starting place for consideration of key lessons for practice, service planning and policy. Foremost among these is that those planning and providing care to women with FASD need to adopt a wholistic approach and understand women's substance use within the context of all facets of their life and community contexts. While this finding may not seem new or surprising – indeed, the importance of a wholistic approach in working with substance using pregnant or parenting women has been consistently emphasized as best practice in the literature for years (Motz et al, 2005; Niccols & Sword, 2005; Parkes, Poole, Salmon, Greaves & Urquhart, 2008; Poole, 2011), our interviews with women with FASD underscores the urgency of this approach.

A second key lesson is that women with FASD most likely will not self-identify as having a neuro-developmental disability, especially in the initial stages of program intake. Thus, program staff and managers need to be attuned to the likelihood that some of the women with whom they are working may have FASD. Further, this means that service providers must be knowledgeable about FASD and its behavioural characteristics, as well as about the range of program-related adaptations and accommodations that are key to removing barriers to access and to promoting women's success within services.

In terms of promising approaches to substance use treatment, the themes emerging from our interviews with substance using women with (suspected) FASD were both consistent with the existing literature on women-centred care and also helped us to further delineate key practices that were specifically informed by an FASD-lens and made a positive difference for women with FASD.

Women spoke clearly and passionately about the value of a trusting relationship with a service provider wherein they felt safe, could speak honestly and get honest guidance in return, and were not judged, blamed or shamed. This relational approach dovetails with the need to work with women where they are at and to tailor support and interventions in keeping with women's readiness for change and their needs in various areas of their life – i.e., additional promising approaches in working with women with FASD include a need to focus on women's readiness for change and thus the use of motivational interviewing techniques, albeit adapted for women with FASD (Dubovsky, 2009; Grant et al. 2009) as well as a wholistic and women-centred approach to services and care (Network Action Team on FASD Prevention from a Women's Health Determinants Perspective 2010a; Network Action Team on FASD Prevention from a Women's Health Determinants Perspective 2010b).

Synthesis of findings across our project's three components

Although this article has focused exclusively on findings from our interviews with women with (suspected) FASD, the promising approaches that emerged from these interviews were highly congruent with our findings from the other components of this project – i.e., with the findings from our literature review and our interviews with service providers (Gelb & Rutman, 2011; Rutman, 2011).

Indeed, when the project's findings were synthesized, what emerged was a set of promising approaches that led off with emphasizing the pivotal importance of mandatory training in FASD, along with ongoing mentoring and supervision, for service providers, managers and students involved in alcohol and drug counselling, clinical counselling, mental health services, social work and child welfare, and other human service professions. Further, an important promising practice identified in relation to training was that it take into consideration the support needs of the practitioner learners, who themselves may have experienced violence, trauma and problematic substance use (Gelb & Rutman, 2011; Rutman, 2011).

Other key promising practices delineating elements of an FASD-informed approach included: *adapting the program's physical environment* to promote a calming and welcoming space (e.g. reducing noise levels or visual clutter); *making program-related 'accommodations'* to help ensure participation and successful program outcomes (e.g. reminder calls and transportation assistance; consistency in program timing; flexibility for late arrivals or missed appointments; extended timeframes for program duration; and flexibility and/or adaptations in group programming and process); *adapting communication* and motivational interviewing techniques; *employing wholistic and collaborative approaches* to programming (e.g., family-accessible programs and/or child care resources; collaborating with child welfare services to address issues related to child protection; liaising with supportive housing options; peer-based support and mentoring); and *resourcing programs adequately* to enable "care for the caregiver" such as smaller case loads and service provider supervision and support.

Conclusions and directions for change

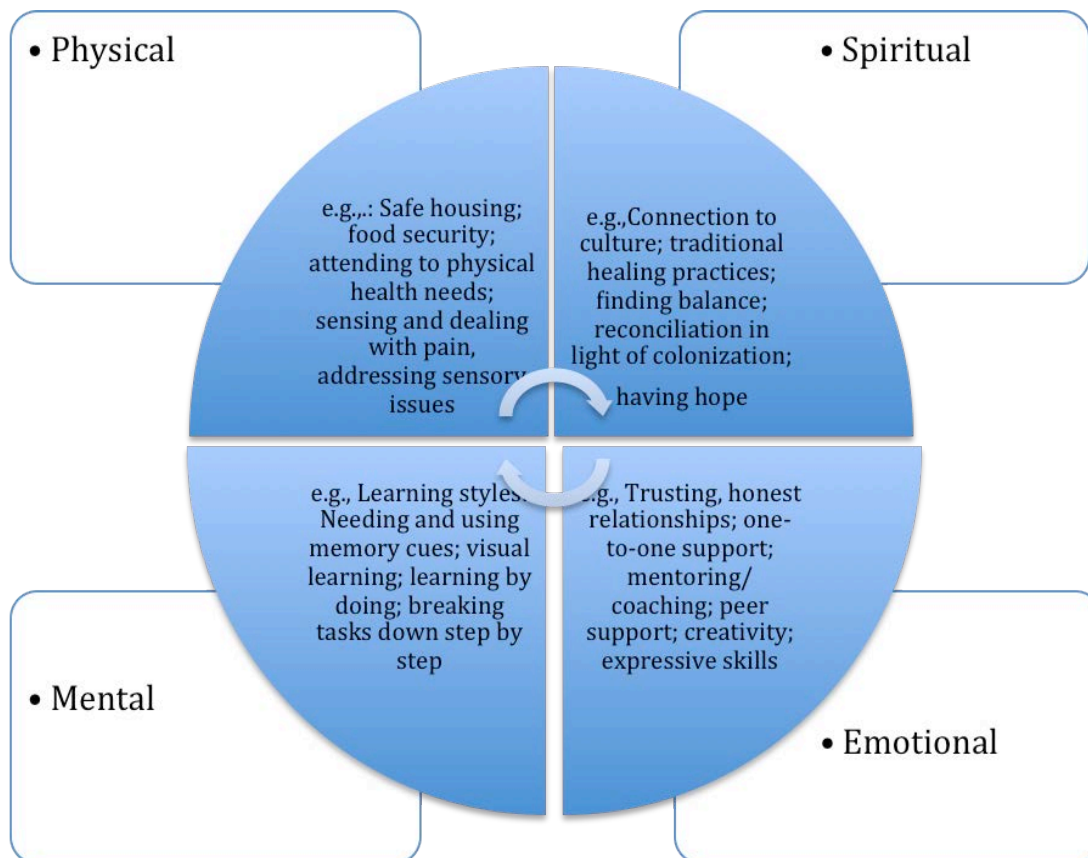
By way of conclusion, we emphasize that substance use treatment programs serving women with FASD need to be designed and implemented using both FASD-informed and women-centred theoretical frameworks. It is the braiding together of the FASD-lens and the gender-lens that gives rise to promising and appropriate approaches for women who have FASD.

In working with women with FASD, professionals must have a clear understanding of each woman’s life circumstances and her social and cultural context, including her strengths, experiences, needs, readiness for change, and the barriers she may have faced in accessing or participating in services in the past.

To date, the predominant frameworks for conceptualizing the behavioural characteristics, issues/difficulties, needs and strengths of people with FASD have been guided by disability-focused or neuro-behavioural paradigms (Malbin, 2002; 2011; Streissguth et al, 1996). These frameworks have significant value, particularly in informing and reminding professionals, policy makers, families and community members alike that FASD is a brain-based, invisible disability, and thus the onus lies with all of us to (re)interpret behaviours and shift expectations accordingly (Malbin, 2012; 2011).

At the same time, our project’s findings and their implications have led us to develop and put forward another framework for conceptualizing both FASD effects and FASD-informed approaches; this framework is shown in Figure 1. At the core of this framework is the guiding value of being wholistic and of recognizing FASD-related strengths, goals, needs, and challenges across multiple dimensions, including physically, mentally, emotionally and spiritually. A framework such as this one could also be used to explore possible FASD effects and FASD-informed approaches from the perspective of the individual, family, community and nation, and over different points in the lifespan and into future generations.

Figure 1: FASD-Effects, FASD-informed Approaches Considered Wholistically



We suggest that a wholistic, wheel-based framework such as this one is not at odds with a neuro-behavioural model; indeed, the different frameworks may be seen as being complementary. The value of a wheel-based framework, however, may be its ability to reflect and weave together multiple ways of considering the strengths, experiences and support needs of people living with FASD, and also understanding FASD within different cultural contexts, including traditional Aboriginal contexts that recognize the inseparability of different domains of health, spiritual knowledge and practices, and well-being (Chansonneuve, 2005; Van Bibber, 1997). Indeed, the circular framework depicted in Figure 1 is congruent with and has been informed by Indigenous wheel-based frameworks of well-being that emphasize the inter-connectedness of all aspects of existence, phases of the lifespan and future generations, as well as the importance of wholistic approaches to healing and understanding (Kryzanowski & McIntyre, 2011). Further, since both Aboriginal and non-Aboriginal women in our project spoke of the value of wholistic programming and care, this framework is suggested as a universal approach in working with both Aboriginal and non-Aboriginal women and individuals living with FASD and their families.

Finally, the wheel-based, wholistic framework also may remind us of the pivotal need for other key values, such as compassion, respect and collaboration, which, as demonstrated by women's voices, are at the core of FASD-informed care.

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An Interdisciplinary Journal

Honoring the Voices, Perspectives and Knowledges of First Peoples through Research, Critical Analyses, Stories, Standpoints and Media Reviews

Capturing the experiences of FASD prevention workers through quilting

Erin Atkinson,¹ Jenelle Job,¹ Jacqueline Pei,² Cheryl Poth,³ Teresa O’Riordan,⁴ and Lin Taylor⁵

¹ M.Ed., Department of Educational Psychology, University of Alberta, Alberta, Canada

² Ph.D., Canada FASD Research Network, British Columbia, Canada

³ Ph.D., Department of Educational Psychology, University of Alberta, Alberta, Canada

⁴ B.Sc., Executive Director, Northwest Central Alberta FASD Services Network, Alberta, Canada

⁵ M.A., Registered Psychologist, quilter

Corresponding author: Erin Atkinson, ematkins@ualberta.ca

Abstract

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 Fetal Alcohol Spectrum Disorder (FASD) prevention workers in the Parent Child Assistance Program (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.

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, 2009). 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

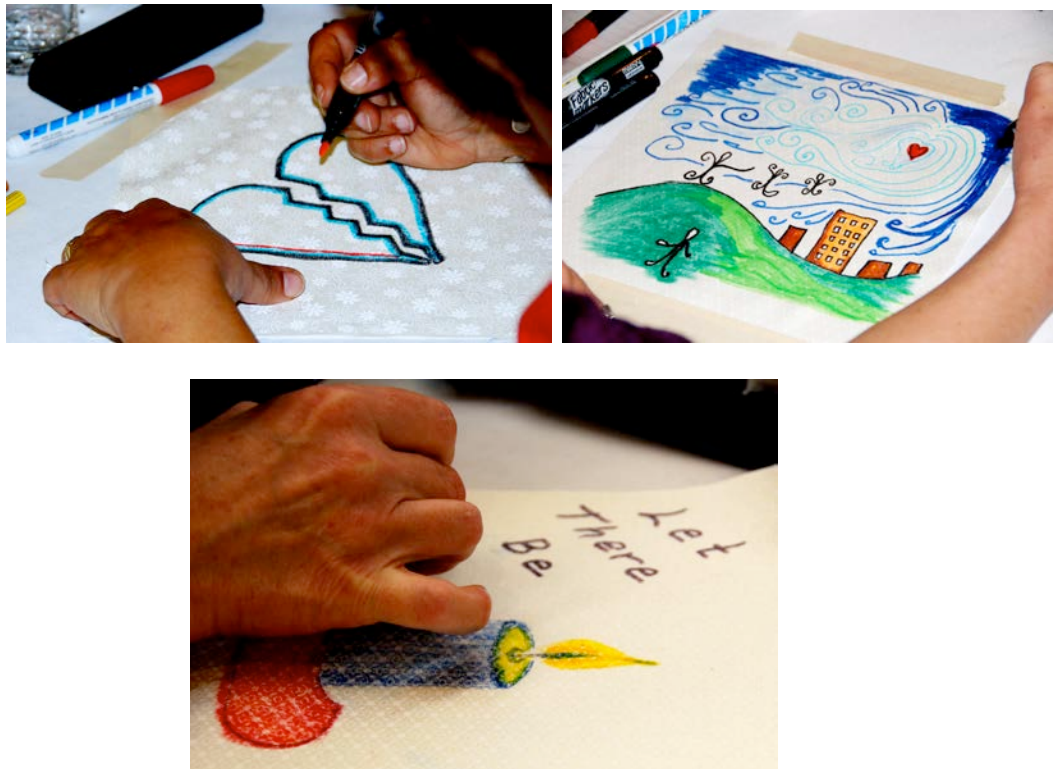
This quilting project was undertaken as part of a larger examination of FASD service delivery in Alberta. Specifically, the purpose of this project was to explore PCAP prevention workers' experiences working on the front lines of FASD prevention efforts in the province. These experiences were collected 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, & 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*, pictured below. The quilter chose this name to reflect the challenging nature of a PCAP mentor's work, which involves supporting at-risk mothers in often 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. 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...unconditional positive regard....That is what we need to give is 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 often 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, Metis and Inuit peoples.

Acknowledgements

The authors would like to acknowledge the members of the Alberta Clinical and Community-based Evaluation and Research Team (ACCERT) for their role in collection and analysis of data and the dissemination of findings related to this project. Additionally, this research would not have been possible without the participation of the men and women of PCAP, whose passion and dedication to their work is both noteworthy and inspiring.

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An Interdisciplinary Journal

Honoring the Voices, Perspectives and Knowledges of First Peoples through Research, Critical Analyses, Stories, Standpoints and Media Reviews

An examination of three key factors: Alcohol, trauma and child welfare: Fetal Alcohol Spectrum Disorder and the Northwest Territories of Canada.

Brightening Our Home Fires

Dorothy Badry¹ and Aileen Wight Felske²

¹ PhD, RSW, Faculty of Social Work, University of Calgary, Calgary, Alberta, Canada

² PhD; R. Psyc. Mount Royal University, Calgary, Alberta, Canada

Corresponding author: Dorothy Badry, badry@ucalgary.ca

Abstract

This article was generated from the research project “Brightening Our Home Fires” (BOHF), a Photovoice project on woman’s health and wellness that took place in the Northwest Territories (NT) from 2010–2012. This research was funded by the First Nations and Inuit Health Branch (FNIHB) of Canada. Approximately 30 women from four different communities in the NT participated in this project; Behchokö, Ulukhaktok, Yellowknife and Lutsel 'ke. The method utilized in this study was Photovoice, a Participatory Action Research (PAR) model that is identified as a qualitative research approach. While the research project was a Fetal Alcohol Spectrum Disorder (FASD) prevention project, the broader focus was on issues related to health and healing within a northern context in the NT from the perspective of northern women, and within the construct of health. The primary focus of this article is the presentation of a model that was generated from a review of the research literature gaining a deeper understanding of broader social concerns in the NT. Three key factors are highlighted as critical in developing a deeper understanding of the context of women’s health issues that are important to consider in FASD prevention work: 1) trauma, 2) alcohol abuse and 3) child welfare involvement and the impact on communities in the northern territories of Canada as it presently exists in the NT. This research served to provide a broad perspective of social problems that may be mitigating factors in the presentation of FASD in a northern context.

Key words: Northern Canada, alcohol, trauma, child, welfare, FASD, Aboriginal, Photovoice, social determinants of health

Authors’ Note: This paper is part of the Brightening Our Home Fires project. It is the first in a series of three articles in this journal: 1) An Examination of Three Key Factors Alcohol, Trauma and Child Welfare: Fetal Alcohol Spectrum Disorder and the Northwest Territories of Canada, Brightening Our

Home Fires; 2) An Exploratory Study on the Use of Photovoice as a Method for Approaching FASD Prevention in the Northwest Territories; and 3) Healing through Photography – A Reflection on the Brightening Our Home Fires Project in the Remote Hamlet of Ulukhaktok, Northwest Territories. Together these three articles provide a comprehensive introduction and overview of this project that took place in the NT from 2011-2012. These are the first publications on this research. This project received funding from the First Nations and Inuit Health Branch, ethics approval from the Conjoint Faculties Research Ethics Board at the University of Calgary and a research license from the Aurora Research Institute after a process of community consultation with different communities engaged in this project. These papers are of interest to researchers, practitioners and educators in the north.

Introduction

The focus of this paper is to review relevant literature that supports a deeper understanding of the health and social health context in northern Canada. Since July 2009, a team of researchers and service providers working in the NT have been collaborating to develop a research project in the NT that explores the issue of trauma in the North, its relationship to alcohol use and the prevention of FASD. The Canada FASD Research Network (formerly known as the Canada Northwest Research Network) has, within its structure, a series of Network Action Teams (NATs). Individually and collectively, members of the NATs have access to a wide knowledge base in community work and research that provided a strong foundation to support the BOHF project (Badry, 2012). Membership of the research team included representatives originally from British Columbia, Alberta, Saskatchewan, Manitoba and the Northwest Territories. Membership has now expanded across the country of Canada. Monthly meetings are held to review research, discuss projects and develop knowledge and information on FASD as it relates to women's health concerns within the broader context of their lives. The NAT focused on Women's Social Determinants of Health as it relates to FASD and women's health concerns linked researchers and service delivery members with concerns specific to the North West Territories. The BOHF project was developed with an understanding that prevention is best achieved through informed research that translates gathered knowledge into meaningful and practical forms that can be shared with, utilized and implemented by, local communities. While FASD prevention is a concern, the focus of this paper is on the broader context of critical factors in the NT that form a background for this work, including identification of health and social issues that are key considerations in any prevention work. Literature reviewed included academic journals in social work, health and the north, as well as government reports, and articles of interest by FASD networks.

Context for FASD prevention work

The issue of FASD prevention must be addressed in Aboriginal and Inuit communities from a cultural, historical, political and social context, that respects the past, considers the present, and holistically addresses concerns with these influences in mind. As the BOHF research focused on a highly sensitive and potentially stigmatizing issue such as maternal substance use and FASD, the approach to this project had to be constructed and embedded within communities through local contacts, discussions, conference calls or meetings whenever possible. Given the broad distances between communities in the NT, forms of communication amongst the team and the communities was often done via e-mail, Skype and phone conversations. Visits to each community took place throughout the project and team members travelled to communities to engage in the primary Photovoice work.

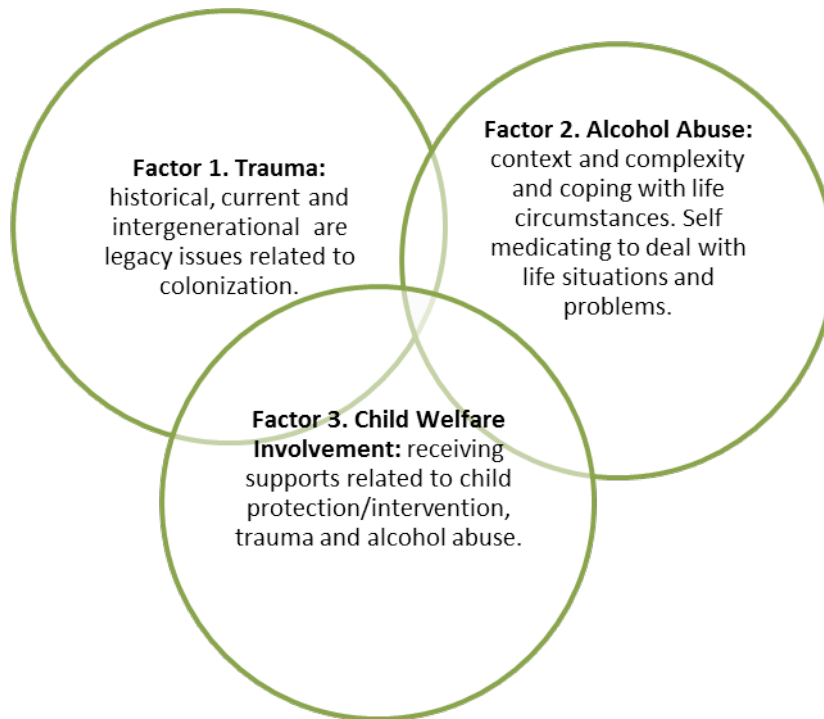
While the need for culturally-responsive and culturally-safe models of FASD prevention that directly addresses relationships between trauma, substance use, and FASD among Aboriginal peoples has long been identified, there remains a lack of resources to develop and implement such interventions at the community level. There is also a lack of resources to support linked, community-based research in the North evaluating intervention effectiveness (Salmon & Clarren, 2011.) While some resources exist in the NT for women struggling with health and social issues, the great distances between communities can be a barrier to readily accessing supports. Service for women in need of help and struggling with addictions, trauma and domestic violence is more readily available in larger centers such as Yellowknife, NT, than in smaller, remote communities. The Centre for Northern Families (CNF) is one example of a resource center for women that provide shelter, access to health and other supports as required. These efforts are thus in a neophyte stage in Canada, and developing a Northern agenda is critical to supporting families in the North who often do not have access to resources locally. Highlighting these issues through research is important to developing supportive interventions, resources, programs, and policies that respond to the needs of communities.

In 2011 the National Collaborating Centre for Aboriginal Health, report author, Dr. Emilie Cameron, published *State of the Knowledge: Inuit Public Health* specifically suggesting there is a gap on comprehensive health data on FASD and associated disabilities. The *Inuit Five-Year Plan for Fetal Alcohol Spectrum Disorder: 2010-2015* was published by Pauktuutit – Inuit Women of Canada and indicates that, although learning disabilities are identified, there is no comprehensive source of information that identifies children with FASD. There is growing awareness of the need to address these concerns, but a consistent infrastructure does not exist to supports children and families with these problems. This issue falls under the broader rubric of mental health and addictions and concerted efforts are being made to address these issues within Inuit communities in Canada. Alcohol is implicated in most episodes of violence, and a large percentage of injuries in the North (Inuit Tapiriit Kanatami (ITK), 2007). In addition, the main reason for most mental health hospitalizations for both women (48%) and men (65%) were substance related disorders. The heaviest drinking is amongst young people 15-24 closely followed by those aged 24-39. This includes the abuse of alcohol or withdrawal from alcohol (Northwest Territories, 2010, 201.) Badry (2012) wrote the Brightening Our Home Fires in the Northwest Territories Final Report. In evaluating the literature on key areas such as trauma, child welfare involvement and alcohol abuse for this report to the First Nations Inuit Health Branch, that themes emerged regarding the social concerns identified in Model 1.

Model 1

Brightening Our Home Fires: Model of Factors Related to Understanding Fetal Alcohol Spectrum Disorder in a Northern Context:

Trauma, Alcohol Abuse and Child Welfare Involvement (Wight Felske & Badry, 2012)



Factor 1: The **trauma** response to, and legacy of, residential schooling

Factor 2: The statistics on **alcohol abuse** and consumption

Factor 3: The statistics on **child welfare involvement**, and children receiving care from the government because of family problems and issues related to this intervention.

These indicators can be used to form social policy regarding FASD that informs approaching FASD from a cultural lens that is respectful of history while moving a health agenda forward. It targets FASD as a preventable problem while attaching intensive supports to at risk families with a goal of child and family health. This harm reduction model identifies a triad of factors that underlies the problem of FASD.

The three key areas identified above will be reviewed in greater detail in relation to existing literature and highlight in greater details the issues associated with each factor, trauma, alcohol abuse and child welfare involvement.

Factor 1: The trauma response to and legacy of residential schooling: Historical, current and intergenerational legacy issues related to colonization

When considering the diagnosis of a child, youth or adult with FASD, it is crucial to recognize that women who use alcohol during pregnancy are not doing so to harm their child. The broader issue of substance abuse is a symptom, and legacy, of multifactorial causes. The roots of trauma in Aboriginal, Metis and Inuit communities can be found in the legacy of the colonization of Canada. In Northern Canada, disruption of the family systems and structure, the marginalization from resources, including cultural resources, and the imposition of federal and provincial policies and laws worked together to create challenging conditions for families. Caron (2005), a physician, wrote about the disproportionate risk of injury and illness related to trauma in the North. Mortality rates are twice that of Canadian population, with one third of deaths caused by trauma. She advocates the importance of documenting morbidity and mortality caused by trauma in Aboriginal communities and to study the contributing factors and root causes in greater detail, beyond surface representations (Caron, 2005). Finding solutions to develop better emergency treatment through studies with Aboriginal and Inuit people and the need for better services is essential but often inhibited by the rural and remote nature of some communities. Sometimes, the cumulative impacts of multi-abuse trauma resulted in the disintegration of families, communities, and systems of wellness. Along with the disintegration of wellbeing, the use of alcohol to self-medicate arises and the emergence of FASD becomes a concern.

Unresolved issues related to past traumas and historical abuses are problematic, as they can lead to self-medication through alcohol use as a coping mechanism. Chansonnueve (2005) identifies signs of unresolved trauma as flashbacks, nightmares, intrusive thoughts and engaging in repetitive patterns of behavior. In children such trauma can be seen in behavior that appears disorganized, chaotic and feeling agitated (p. 53). Individuals and families who do not come to terms with their traumatic experiences are likely to pass on the unresolved trauma to their children. Childhood trauma can be hidden or stored in brain circuits, and later activated by adult trauma, particularly trauma in intimate relationships. Studies on trauma and the connection to parenting have shown a linkage between childhood trauma and progressive substance abuse (Connell et. al., 2007; Wesley-Esquimaux, and Smolewski, 2004).

Intergenerational trauma is commonly used to describe trauma experienced by Aboriginal families. It is most often associated with residential school experience. It may also be the result of such actions as forced relocation, apprehension by social services, and hospitalization. Intergenerational trauma is described by the Aboriginal Healing Foundation report: “When trauma is ignored and there is no support for dealing with it, the trauma will be passed from one generation to the next. What we learn to see as “normal” when we are children, we pass on to our own children” (Aboriginal Healing Foundation 1999, A5).

Multi-abuse trauma involves active forms of abuse (e.g. sexual assault, domestic violence, child abuse or neglect, emotional/psychological abuse) and coping forms of abuse (e.g. substance abuse, compulsive eating, self-harming behaviors) (Edmunds & Bland, 2011). Researchers examining stress in Aboriginal people with diabetes found stress to be multifaceted and intertwined. Intertwined stress includes: health related stress; economic stress; trauma and violence; as well as historical cultural political stress linked to identity (Bartlett, Madariaga-Vignudo, O’Neil, and Kuhnlein (2007).

The same study also found that the people drew upon cultural teachings and practices to deal with their stress. The most profound trauma affecting Aboriginal communities across Canada can be traced to the residential school experience. Trauma is a complex condition that is dependent upon a number of factors, such as age, timing of abuse, relationship with the abuser and type of abuse. Residential schools perpetuated multi-abuse trauma upon Aboriginal children. Children were taken from their families for months and sometimes years, where they were stripped of their connections to family and culture. The children suffered many abuses, and their families were powerless to protect them. Survivors and their descendants continue to live with the historical and intergenerational trauma (Chansonneuve, 2007). Trauma experience produces feelings of anomie (normlessness), powerlessness, vulnerability, frustration and confusion. This destabilizes a person's sense of self and affects identity. The magnitude of pain, rage, and the grief of unresolved trauma continue to haunt families and communities into present times, and it is a naive notion that people simply get over trauma (Chansonneuve, 2007).

Today there are addiction treatment programs that focus on the links of trauma and addictions as an approach to treating substance abuse. Learning about the historical roots to trauma can help to find workable solutions by, and for, community members. Understanding constructs such as dislocation and colonization are critical in treatment. Dislocation means "being removed from one's language, culture, family and community" (LaRoque 2001, 1). Dislocation is a situation that has affected Aboriginal children sent to residential schools, as well as immigrants and refugees to Canada. The construct of colonization refers to "that process of encroachment and subsequent subjugation of Aboriginal peoples since the arrival of Europeans. From the Aboriginal perspective, it refers to the loss of lands, resources, and self-direction and to the severe disturbance of cultural ways and values" (LaRoque, 2001 p.1). Today there is a greater understanding of the dynamics of violence and trauma and the connection to coping abuse, such as substance abuse (Edmund & Bland, 2011; Chansonneuve, 2005). There is also a better appreciation of the strengths within Aboriginal communities and traditional knowledge and practice (Fallot & Harris, 2009).

Factor 2: Alcohol abuse. The statistics on alcohol abuse and consumption are important to consider in terms of context, complexity and coping with life circumstances through self-medicating.

Alcohol abuse is a challenging problem in the North, with heavy drinking occurring primarily in younger segments of the population. The primary source of information on alcohol use is from the Northwest Territories (2010) *Health Status Report* which describes heavy drinking as occurring at least once per month among people 15 years of age and older. Participants are grouped by gender, age, and rural / urban location. The percentage of youth, ages 15 – 24 (62%) and adults, 25- 39 (52%) engaging in heavy drinking during their reproductive years is of great concern. While the overall percentage of men engaged in heavy drinking (56%) is higher than women (37%), the gender division cannot be examined separately as male partners (as well as friends and sisters) tend to encourage drinking activity among women regardless of pregnancy status. In this report it is stated that the 2002 NT Drug and Alcohol Survey results when compared to the 2006 data, indicated that the frequency of alcohol consumption for those drinking during pregnancy has not shown a reduction. Additionally, the main reason for most mental health hospitalizations for both women (48%) and men (65%) were substance related disorders. This includes the abuse of alcohol or withdrawal from alcohol. Between 2003 and 2007, 39 NT residents

committed suicide, for an overall average rate of 1.8 per 10,000 (population) per year (Northwest Territories, 2010, p.56) and reflective of a much higher proportion than the national average of 1.1 per 10,000 (population). These statistics in each area – alcohol consumption, mental health hospitalizations and health complications related to alcohol use, are interwoven. Alcohol is implicated in most episodes of violence and a large percentage of injuries in the North (Inuit Tapiriit Kanatami, 2007). The number of infants born with FASD is unknown as prevalence data is not yet tracked consistently across Canada.

Factor 3: The statistics on child welfare involvement and children receiving care from the government because of family problems and issues related to this intervention.

Identifying child welfare concerns within this paper is important as it contextualizes concerns for children and families. Our society places the responsibility to protect and nurture children with biological parents/legal caregivers. While birth families may be involved in the support of their child with an FASD diagnosis, the reality is many find that the difficulties in their own lives, related to poverty, alcohol abuse, histories of trauma and housing instability, overwhelm the possibility of taking on such exceptional parenting. Caregivers representing the state such as foster or adoptive families quickly become engaged in the parenting process once children are removed from familial care. Child protection agencies are responsible for investigating all allegations of child abuse or maltreatment and intervening when necessary. This decision making process is the sharp edge of ethical reasoning, as removal of a child from their home is traumatizing. The standing concern of children with disabilities such as FASD and the ability of parents to respond to such needs becomes a factor in decision making. Involvement in child welfare is stigmatizing in the North, and less well hidden than in large urban cities. Additionally, agencies are mandated to provide support to families facing challenging circumstances in order to ensure the safety and wellbeing of children (North West Territories, 2010). The report states: “Children may receive services because they were abused or neglected. Other children may come into care voluntarily and/or receive services because they have unmanageable behavioral problems resulting from developmental delays, mental health issues or Fetal Alcohol Spectrum Disorder”, (p. 70). Another concern noted in this report was that drug and solvent use was identified as a major factor in referrals for Child and Family Services.

Table 1: The NWT report summarizes the involvement by child welfare in the territories

Status	2005	2006	2007	2008	2009
Total (March 31 of each year)	581	613	601	594	611
Total - Court Involved	326	346	354	358	321
Permanent Custody Order	213	221	226	227	212
Temporary Custody Order	84	89	88	90	77
Supervision Order	20	23	18	20	22
Apprehension	9	13	22	21	10
Total - Voluntary	255	267	247	236	290
Plan of Care Agreement	139	152	113	124	184
Voluntary Services Agreement	86	85	103	81	79
Support Services Agreement	30	30	31	31	27

Source: Department of Health and Social Services, NWT Data extracted as of July 13, 2009.

70. Retrieved online from http://www.hss.gov.nt.ca/sites/default/files/nwt_health_status_report.pdf

In 2009, according to the Northwest Territories (2010) *Health Status Report*, 611 children were receiving services and approximately 53% of these children (321) were receiving services through a court order (apprehension, permanent custody order, supervision order and temporary custody order), with the remaining 47% (290) receiving services through a family-based agreement (plan of care agreement, support services agreement and voluntary services agreement). This report suggests that parents having a drug or solvent problem have consistently been the top cause of CFS referrals in the NWT since 2004. The impact of child removal in small communities is direct. Foster care may not be available in the same community, or relocation may be necessary due to lack of local resources. In respect of Northern context and reality, cultural practices, such as Custom Adoption, are utilized when possible within families and communities. Underlying this practice is a broad based cultural intervention. When children from remote communities are subject to adoption, the practice of maintaining home ties wherever possible is important to the future of the community.

Across the provinces, and territories, a range of policies exist relating to the state's role in supporting a healthy home life. However, the number of children either removed from the care of their parents or guardians or receiving Child and Family Services (CFS) in their own homes are indicators of these continuing crises (NWT, 2010). The NWT territorial government has started to consider policies looking at costs and outcomes. Factors such as poverty and lack of a consistent resource infrastructure across Northern communities are a reality that contributes to the above noted issues of child welfare involvement, alcohol abuse and trauma. The information presented in this paper regarding child welfare involvement is important, as child welfare interventions are deeply interwoven into grief and loss issues for children, families and communities. The need to identify interventions that are holistic and restorative is crucial in moving forward in FASD prevention and supports.

In Canada, governments generally provide services to children and families under an umbrella of provincial or territorial child welfare. While this has resulted in a broken road for Canadians who wish to relocate, and differing systems exist from province to province in relation to supports related to FASD, this structure provides a framework to examine these concerns. At present, only the Yukon has directly addressed the issue of FASD in its legislation (Children's Act Revision, 2005). Alberta has developed an FASD 10-Year Strategic Plan, published in 2008, and suggests that all government ministries include priorities regarding FASD within their operational plans (Government of Alberta, 2008). One report that specifically calls for public policy development in relation to the social determinants of healthy pregnancy hails from British Columbia (BC). The report *Understanding Fetal Alcohol Spectrum Disorder: Building on Strengths* reviews strategic initiatives as of 2003 in BC and outlines future plans and strategies strongly related to women's health. Child welfare involvement for families of children with FASD is a challenge because supports are needed to work with the child with disabilities and they do not always exist in small and remote communities. This has been identified as a concern by Pauktuutit Inuit Women of Canada (2010) in their environmental scan of services and gaps in Inuit communities. A common consensus from these reports and researchers is the need to develop capacity around diagnosis follow-up supports, awareness and interventions.

Discussion

Identifying three key factors that are prominent in the discourse about Northern social health is a critical step in providing a broader framework for prevention and intervention. The three factors; trauma, alcohol abuse and child welfare involvement, and the impact on communities in the northern territories of Canada are underlying foundations in any discussion on FASD prevention. The discourse and dialogue on prevention of FASD is somewhat fragmented in rural and remote communities across Canada, not just the North, for a number of reasons. In rural communities access to resources, such as diagnostic clinics, does not exist within the health care system in a similar fashion to communities in larger, urban centers. While efforts are made to refer for diagnosis – an important tool in planning interventions and effective supports for children and youth with FASD, families in the North are disadvantaged in accessing such resources. Responding to FASD as a health issue places it squarely within a health model and framework and hopefully resources will follow accordingly. While broad awareness exists of FASD as a public health issue the root causes of FASD identified within this paper warrant further examination.

An FASD research lens

The Canada FASD Research Network Action Team on Prevention developed a consensus statement for FASD prevention. One of the 10 fundamental components is being trauma-informed:

Multiple and complex links exist between experiences of violence, experiences of trauma, substance use, addictions, and mental health. It is important to understand that at times, research initiatives, policy approaches, interventions, and general interactions with service providers can in themselves, be re-traumatizing for women. When a woman seeks out treatment or support services, practitioners have no way of knowing whether she has a history of trauma. Trauma-informed systems and services take into account the influence of trauma and violence on women's health, understand trauma-related symptoms as attempts to cope, and integrate this knowledge into all aspects of service delivery, policy, and service organization (CanFASD, 2013).

In putting this model forward it is our hope that a deeper appreciation of history and context is considered in relation to intervention around FASD that is rooted in the experiences of women prior to giving birth to a child with FASD. The broader underlying issues of historical trauma that are not only rooted in women's lives, but also in wider community histories should inform compassionate and caring responses to the prevention of FASD that are grounded and supported within community based circles of caring.

Conclusions

There are key areas that require a strong focus in prevention of FASD from a women's' social determinants of health lens such as maternal health. We did not directly report on the qualitative data in this article from the BOHF project that work has influenced this article and highlighted the need for a close look at relevant literature. It was abundantly clear that, to women participants, the well-being of their children is highly important as this was so often mentioned. For women struggling with addiction, counseling that supports a harm reduction framework must be considered. Women with addiction issues are exposed to a great deal of harm and experience a lack of safety, particularly women who are homeless in the NT and dealing with unresolved trauma.

A research agenda that examines FASD in the North is moving forward as projects that work within communities and support local networks are evolving with support from the Canada FASD Research Network. Engagement in this project has opened some dialogue and a body of literature is emerging on Inuit concerns related to FASD (See Appendix 1). Women who are supported to have healthier lives will benefit in all other areas of their life including maternal health. Other supports include urgent access to addictions treatment for alcohol and drugs as well as smoking reduction and cessation. Our model presented three factors, 1) trauma, 2) alcohol abuse and 3) child welfare involvement which underlie FASD prevalence, it is recognized that supportive and accessible resources in responding to each of these areas will have a broader impact of the physical, social and mental health of communities.

Future research on FASD prevention in the north should consider the impact of major changes in the identified factors. For example, child welfare systems based on extended family strengths could alter the perception of northern families when faced with government intervention. Social and political locations for information on FASD prevention should be examined in terms of community histories, and partnerships with education and health should be used to promote critical intervention models. The need for FASD prevention should be multifaceted, grounded in women's and community health frameworks and supported in local, community based initiatives.

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Appendix 1

Inuit specific resources

An important body of literature is emerging on this topic and identifies the need for Inuit specific social determinants of Health. Examples of research-based documents include:

- Ajunngingiq Centre & National Aboriginal Health Organization. (2006). *Fetal Alcohol Spectrum Disorder: An environmental scan of services and gaps in Inuit communities*. National Aboriginal Health Organization.
- British Columbia Centre of Excellence for Women's Health. (2007). *Preventing FASD through providing addictions treatment and related support for First Nations and Inuit Women in Canada*. British Columbia Centre of Excellence for Women's Health. Retrieved from: www.coalescing-vc.org.
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An Interdisciplinary Journal

Honoring the Voices, Perspectives and Knowledges of First Peoples through Research, Critical Analyses, Stories, Standpoints and Media Reviews

An exploratory study on the use of Photovoice as a method for approaching FASD prevention in the Northwest Territories

Dorothy Badry¹ and Aileen Wight Felske²

¹ PhD, RSW, Faculty of Social Work, University of Calgary, Calgary, Alberta, Canada

² PhD; R. Psyc. Mount Royal University, Calgary, Alberta, Canada

Corresponding author: Dorothy Badry, badry@ucalgary.ca

Abstract

The Brightening Our Home Fires (BOHF) Project was a project that took place in four communities in the Northwest Territories (NT) from 2011-2012. The purpose of this project was to explore the issue of Fetal Alcohol Spectrum Disorder (FASD) prevention as a health concern in the NT, and to develop an approach that was meaningful for women participants. The intent of the project was to develop a culturally-responsive intervention study addressing links between trauma, and FASD prevention from a social determinant of women's health perspective through a Participatory Action Research framework. While the project was intended to explore and inform on the topic of FASD prevention work, the primary research question was: What does health and healing look like for you in your community? Thirty women from four communities participated in this project: Yellowknife, Lutsel 'ke, Behchokö, and Ulukhaktok. This research had differing impacts on participants but an overarching construct was that participation in Photovoice supported women to see their lives in new ways and to reflect upon different struggles and possibilities. Engaging in this research was intended to build relationships, develop community based research partnerships and intended to develop a framework for informing services and practice responses, or enhancements to current service delivery frameworks around FASD prevention and related health concerns.

Authors' Note: This paper is part of the Brightening Our Home Fires project. It is the second in a series of three articles in this journal: 1) An Examination of Three Key Factors Alcohol, Trauma and Child Welfare: Fetal Alcohol Spectrum Disorder and the Northwest Territories of Canada, Brightening Our Home Fires; 2) An Exploratory Study on the Use of Photovoice as a Method for Approaching FASD Prevention in the Northwest Territories; and 3) Healing through Photography – A Reflection on the Brightening Our Home Fires Project in the Remote Hamlet of Ulukhaktok, Northwest Territories. Together these three articles provide a comprehensive introduction and overview of this project that took place in the NT from 2011-2012. These are the first publications on this research. This project received funding from the First Nations and Inuit Health Branch, ethics approval from the Conjoint

Faculties Research Ethics Board at the University of Calgary and a research license from the Aurora Research Institute after a process of community consultation with different communities engaged in this project. These papers are of interest to researchers, practitioners and educators in the north.

Introduction

The goal of the Canada FASD Research Network is to reach out to as many communities as possible, particularly in the north to better understand the unique issues and challenges for this population. The original team for this project was drawn from the membership of the Canada FASD Research Network Action Team (NAT) on Women's Social Determinants of Health that has been meeting monthly since 2007 (See Appendix 1). This project emerged primarily from concerns raised by members of the NAT who resided in the NT and were engaged in women's health issues. While attending the International Circumpolar Conference on Health (ICCH) held in Yellowknife, NT in 2009 a small group strategized and worked on developing a proposal for this project that was subsequently funded by the First Nations and Inuit Health Branch of Health Canada. The construct of women's health served as a foundation for approaching the topic of FASD prevention. The chosen methodology was qualitative and framed as Participatory Action Research (PAR).

Photovoice was selected as a means for engaging women on the topic of FASD prevention and 30 women from different communities were involved in the project. Women were recruited for this project through an invitation to participate that was sent to key community contacts as well as through word of mouth. For example, participants in Yellowknife who experienced homelessness in one centre were invited to the Photovoice workshop. Women participants in Yellowknife had an age range from 28-62. While five of seven women were unemployed, at least one woman who was homeless had a job in the home renovation industry and was trying to get her life stabilized, and another in a part time cleaning job. Another participant attended a full time adult education program. While a few participants joined at the outset, other women who saw the activity over a few days also asked to join in as the excitement about using cameras, taking photographs and creating the Photovoice document increased and garnered interest. Women who were homeless in Yellowknife were both Dene (4) and Inuit (3) and had left their home communities. As this study was exploratory in nature, the research agenda did not identify exclusionary criteria, such as direct experience with FASD. As the foundation of this research was grounded in the constructs of health and healing, the invitation to participate was open to women who were willing to participate and act as key informants to this project. The participants were all adult women who expressed an interest in the project and had participated in community meetings held to consult communities prior to the research and community visits. This article primarily focuses on the experience of women who are homeless and living in Yellowknife, NT and sharing their experiences. These will be represented through images and text provided by the women participants.

This article provides a review of the research project, methodology and approaches, ethical consideration, a discussion on the sensitivity of FASD prevention in a northern context and a discussion on the need for community engagement in this health related prevention approach. This research was community based and intended to be inclusive of women with distinct ideas, culture and ways of expressing impressions and thoughts. Photovoice provided an inviting approach to engage with women in the BOHF project. Although this research was carried out specifically in the NT we believe that the approach has merit for other territories and may be of interest more broadly to Northern communities.

Primary goals of the research

As a research team, our vision for this research project included:

- Supporting the voices of women in the NT through Photovoice
- To become informed of what constitutes health and healing from a women's perspective in distinct Northern communities
- Engage in community networking, supporting local, health related community initiatives
- Developing knowledge about FASD prevention from a health perspective lens in a Northern context in a way that was engaging and meaningful for women.

As a means of introduction, the photograph below speaks volumes about the Brightening Our Home Fires (BOHF) Project. This image, taken by one of the researchers, can have multiple interpretations, and in relation to this project represents a meeting between technology, such as a digital camera, and a camera case made using local resources. After the workshop introducing the Photovoice project was adjourned in a remote community, a woman went home and created her own camera case. This creation offered a symbol of the community context, representing engagement in the project and the care and effort that went into the women participants' work, while at the same time conveying the skill, knowledge and talent of the participant.

Image 1: Digital Camera and Hand Made Camera Case



The prevention of FASD is an interdisciplinary concern that is dominantly rooted in discourse that crosses into the areas of addictions, women's health, and child protection issues. This Photovoice project originated from concerns identified in the Northwest Territories by members belonging to the Canada FASD Research Network Action Team (NAT) on Women's Social Determinants of Health. Members of the NAT who had interests in women's health concerns in the North and an appreciation of the realities of access to health services in rural and remote communities joined the research team. As a group, the NAT has had a number of discussions in monthly meetings about the topic of FASD prevention and approaching this issue sensitively and with some caution, due to potential concerns of stigma associated with this topic. A women's health lens provided a framework for project development and identification of the focus of this research.

Taking an appreciative inquiry perspective on a complex health issue such as FASD prevention, and involving Northern women's perspective through Photovoice, offered a way to highlight the importance of adding women's voices to the discourse. This study is health related and considers the needs of Northern women within their communities and context about FASD prevention and related health issues. It is important in any health prevention framework to hear the voices of people living in communities and to raise, from firsthand knowledge and experience, the concern of FASD prevention holistically and within a broader context of women's health. The application of Photovoice as a primary methodology in this research was purposeful and served as a means to explore the lives of women participants in a non-threatening manner. In terms of identifying participants, this research was approached through established local contacts, dialogues and sending out invitations to participate. Individual or small groups were used to collect women's descriptions of the photos taken. Photovoice was found to be a successful tool enabling women of the North to explore their lives.

Brief review of the literature

Fetal Alcohol Spectrum Disorder (FASD) prevention is best addressed in First Nations and Inuit communities from a cultural, historic, political and social context, and thus often takes different forms from mainstream approaches (Salmon & Clarren, 2011). Research in a Northern context needs to be both conceptualized and framed from a perspective that is relevant and realistic. When the research is focused on highly sensitive and stigmatizing issues such as maternal substance use and FASD, there needs to be a critical awareness that such work can contribute to further marginalization of First Nations and Inuit peoples and communities. The paradigm of Participatory Action Research (PAR) is considered an important framework for community based research (Bambra, Fox, & Scott-Samuel, 2005). In the Northwest Territories, the Aurora Research Institute has created protocols for ensuring respectful and ethical partnerships that better support active and collaborative community participation in research. This approach to developing new knowledge can be used by researchers who have an understanding of the community context in which health is studied (Bambra et. al., 2005). Community engagement is critical in designing prevention programs that effectively message the social indicators of health and, in particular, alcohol risks during pregnancy (Pauktuutit Inuit Women of Canada, 2010).

Current literature on Photovoice outlines a methodological approach that generally involves groups and collaborative discussions about photos and captions that represent a particular group or community (Woodley-Baker, 2009; Doyle & Timonen, 2010). For example, one project for homeless women in Calgary, AB, conducted in 2010, was presented at the first *All Our Sisters Conference* held in June 2011 in London, Ontario (Fotheringham, Walsh, & McDonald, 2011) and involved a group of women participant co-presenters. The women that took photos talked about their experiences of moving from being homeless to gaining housing. This group had Photovoice training, took pictures and met weekly for focused discussions, selection of images and development of presentations to be shared. In presenting this research, women participants discussed generally within a group how their pictures capture their voice and vision of their lives within their own context of community. Banks in Prosser (1998) identifies visual anthropology as a means to consider human experience and, in many ways, the Photovoice experience was considered to be a form auto-ethnography. The critical piece that supports this approach is that the interpretation of the images rests with the individual woman taking the pictures. While Prosser (1998) examines the issues related to the status of image-based research, he argues that the nature of this work has not been fully appreciated. Image based research cuts across a wide variety of disciplines within the sociocultural framework and holds deep possibility for exploration of sensitive and deeply personal health related phenomena reflective of lived experience.

The example of a previous Photovoice project entitled *Picture This Photovoice* emerged from Sioux Lookout, ON and was showcased at the Third Annual International Conference on FASD in Victoria, BC in 2008. This project, directed by *Mothers from Sioux Lookout*, presented powerful examples using voice and image to offer critical discourse about the lived experience of being birth mothers of children with FASD and about the needs of their children. In part, this work emerged as part of healing pathway or process for birth mothers, as well as identification of the need to advocate for their children and to encourage deeper understanding of lived experience. This project was part of the *Healthy Generations Family Support Program* and was perceived as critical visual literature that served to support a deeper understanding of FASD from a family perspective. The influence of this work was profound and compassionately portrayed the challenges and gifts of the journey of parents and mothers specifically. This pivotal work clearly identified itself as giving voice to people who are not often heard and was grounded in the lives of women in this community, with a focus on issues such as caregiving and parenting (“Picture this Photovoice,” 2009). This work provides a critical women’s perspective on the challenges, struggles and possibilities for families and children living with FASD.

The broader perspective informing and underpinning this research emerges from understanding FASD prevention from a women’s health determinants lens and perspective as outlined in the Consensus statement prepared by the Network Action Team (NAT) on Women’s Social Determinants of Health (Canada Northwest FASD Research Network, 2010). Work that is respectful, relational, considers self-determination, is women-centered, focused on a harm reduction model, appreciates a trauma informed perspective, is culturally safe and focused on health promotion is crucial. These concepts were formulated through a face-to-face meeting held with members of the NAT who provided the foundation for research values moving forward. Bastien, Carrière and Strega (2009) approach the topic of the distinction between healing versus treatment in an examination of substance misuse and child welfare practice with Indigenous families. While highlighting structural factors that influence these issues Bastien et al. (2009) identify an underlying issue of loss and vulnerability that is persistent and underscores many individual

and community problems; and suggest that healing work, including access to substance abuse services, must appreciate decolonization and understand trauma.

Methodology

This project adopted a qualitative research approach. Qualitative research generally focuses on a phenomenon of interest to particular individuals, such as researchers and communities. Participatory Action Research (PAR) is a narrative form of work that is grounded in the lived experience of participants and gives voice to such experiences from the grassroots. Using PAR as an approach is concerned with research in the social life and within communities that is potentially transformative (Kemmis and McTaggart as cited in Denzin and Lincoln, 2000). The use of Photovoice in the BOHF project enriched a deeper understanding of the context of women's lives and the challenges they face in relation to health matters in the northern parts of Canada, specifically Dene and Inuit women from the Northwest Territories. The pictures women took gave voice and meaning to their lived experiences. Qualitative research utilizing Photovoice as primary methodology positions women participants as co-investigators of the phenomenon of study – in this case an exploratory FASD prevention study in the Northwest Territories.

Critical social research emphasizes the importance of supporting marginalized people with opportunities to share their experiences, to see the connections among these experiences and to create the energy for addressing the root causes of their problems through social change (Freire, 1970). These ideas have been adopted by researchers challenging a positivist research philosophy to become participatory and community based research. Minkler and Wallerstein (2003) described the participatory community orientation as “methods and techniques for helping communities identify their strengths and the problems or concerns they wish to explore” (p. 26). Freire (1970) in his work on disempowering impact of bureaucracy on the poor saw visual images as a way of helping people think critically about their lives.

In the digital world, Wang and colleagues (1997; 2001) first used a visual methodology called photo-voice in connection with a women's health project in China. Women were given cameras to take pictures aspects of their lives and then to use the photographic record to identify 'needs' from their own point of view. Considerable effort was made to enable the photographers to maintain ownership of their images, and then to join in dialogues, discussion and storytelling using this imagery with researchers, policy makers and planners. Woodgate and Leach (2010) used photo voice as a methodology in their study of how Canadian youth frame health within the context of their lives. The study found that lifestyle factors such as healthy eating and exercise dominated the talk of health by youth, and health was seen as a physical lifestyle.

Salmon, Browne, and Pederson (2010) suggest that participatory research offers a relevant framework to involve women in research about their lives and a way to identify and develop “principles that explicate why meaningful, engaged and multi-directional collaboration is essential when conducting studies ‘on the margins’ ” (p. 342). This approach also supports community capacity building, new skill development and the potential to engage in further research work based on findings from the current study. Hunting and Browne (2010) offer their contributions to the discourse on FASD and its' relationship to colonization. They raise critical points about discourse that stigmatizes Aboriginal women and children and suggest that it is important to consider the way in which “health and social experiences often fail to be seen as located within intersection of inequity, racialization, and disadvantage” (p. 48). This notion suggests that

that it is important to consider the ways in which women view their lives, particularly on topics that exist somewhat on the margins, such as FASD prevention in the north. While it is important to examine and discuss this topic in the context of women's lives, it is also important to consider FASD prevention as a health issue in the lives of families and communities.

Engaging in qualitative research that illuminates the lived experience of women such as the BOHF project provided a place to listen, learn, and support women in a creative way. The process of directly working with women, primarily on a one to one basis was very engaging. Women were given cameras that they could use again after the project was finished. In relation to the qualitative analysis process, the images and words become data that are then translated into findings and no exact formula exists (Patton, 2002). As the primary research question focused on health and healing, with a secondary focus on FASD prevention, it was with caution that this question was approached as we appreciated the context and concern of potential stigma associated with asking directly about FASD as a phenomenon. Reviewing and sorting through photographs and text began to offer a critically emerging framework, reflective of the lived experience of women, while sensitively bringing forth experiences related to health and healing. As such, analysis of the data, which is an iterative process leads to awareness of patterns and themes that emerged through multiple reviews and key themes, will be highlighted in this article.

Adjusting the methodology of Photovoice for work in the NT unfolded naturally as it was driven by directly working with the women in their communities and their needs. Another factor was time – when we were in a community the primary focus was working directly and intensively with the women gathering photos, captions, thoughts and ideas as each woman returned with their work. In some cases women worked individually with team members and in some situations group discussions took place. This process was very instructive and Photovoice was distinctly utilized in much shorter and intensive periods of time given the remoteness of some communities. We made adjustments and worked uniquely in each community based on the needs presented in each place.

The important part of engagement with Photovoice was the opportunity to engage directly with personal, lived experience and the opportunity to look at these experiences in new ways, while for some learning a new skill. It was clear that women were very interested in the experience of taking photographs and talking about health and healing as this is an integral part of daily life, even while struggling. Community Based Photovoice as a methodology is grounded in the environment, in the land and the homes where people live and where their day-to-day life takes meaning.

The role of community women in finding culturally relevant interventions aimed at FASD prevention is central to building successful wellness strategies for Northern women. The Photovoice methodology in the BOHF project supported women to express their interpretation of well-being and what healing means to them through photos they take. This community participatory approach to determining wellness indicators requires a respect for a community and its members. O'Neil and Blanchard (2001) suggest that it is crucial to see the world of people, living in their communities, through their eyes and Photovoice presents as a methodology and approach that supports this first hand perspective about lived experience, the importance of the land, healing and health.

Ethical considerations and context

When undertaking work in the Northwest Territories, researchers are required to hold both an ethics certificate and a research license issued by the Aurora Research Institute (ARI). In this case, as the co-principal investigator (Badry) was at the University of Calgary, ethics approval was sought for the BOHF project from this institution. The key role of both the Conjoint Faculties Research Ethics Board (CFREB) of the University of Calgary and the ARI was to consider this research in light of cultural issues and to raise questions about research with a population that is considered potentially vulnerable. To this end a face-to-face meeting was held with the CFREB to review this application, respond to written feedback and answer questions by members of the board that represents faculties across the university after review of the initial submission required by the institutional ethics protocol. In similar fashion, written questions were received from the ARI in a process known as Community Consultation. This project received ethics approval from the Conjoint Faculties Research Ethics Board (CFREB), University of Calgary, and a research license from the Aurora Research Institute, the body governing and approving community based research for the NT, Yukon and Nunavut. The ARI also required and received a copy of the ethics approval certificate.

Context and stigma

With respect to engaging women in the NT in FASD Prevention work it was important to consider how this topic would be perceived and received by potential participants. The research team recognized that this is a sensitive topic and it was very clear that talking about health and healing was contextually appropriate as FASD work needs to be housed within the broader infrastructure of health related prevention and intervention activities. If we were to simply ask what women thought about FASD prevention we would not likely have achieved many results in the project. Thus a significant limitation of FASD prevention work in the NT (and other places) is the stigma associated with FASD and the perception of FASD as a moral problem (Rutman, et. al., 2000; Hunting & Browne, 2010). Activities related to FASD prevention should be more broadly focused on women's health, addiction treatment, and psychosocial supports that consider historical trauma while responding to the challenges faced by women in rural, remote and isolated communities. While Yellowknife is seen as a large urban center within the NT it still has many of the characteristics of a rural community and is a place that many women come to for health interventions and supports. It is important to note that the approach to FASD prevention was primarily exploratory in relation to methodology and approach. However, the use of Photovoice was also purposeful and seen as a way to engage in dialogue on women's health issues. In many ways, this work was a process of *learning on the go* as we moved forward.

Approach to the research

Although Photovoice primarily espouses a methodology of reviewing photographs within a group, we recognized that within this particular context, in a Northern community, the women participants may not be comfortable in sharing their personal viewpoints within a group context. It was clear that working with women individually through reviewing photographs, and creating captions, that a deeply personal process was unfolding. This process required time, attention and one to one engagement. One of the important

things we recognized in this work was the context. In one community we were working with homeless women living in a shelter in Yellowknife, NT. There were issues of trust, of the need for confidentiality, and recognizing that processing the information required private conversations. Some of the restrictions in the environment included space, busyness of the place, people coming and going as other needs are supported such as child-care and a clothing bank. It was a busy location, yet we were able to find a space to work and engage in the way that worked best for the women.

We became aware that a powerful process of engagement was occurring in the midst of this Photovoice project simply through our presence within the space of the shelter. Our process was to meet with women in the late afternoon/evening after our arrival in the community. We spoke to women about the project, providing the documentation about the project and then discussed and signed informed consents with women who wanted to participate. Women who lived in the shelter observed other women showing interest and participating in the project. On the first evening four women signed consents and were provided cameras – some practice and teaching occurred the first evening. It is quite possible that the women spoke amongst themselves the first evening after we left about their interest in the project and, I believe, some excitement about receiving a camera and being able to keep the camera. The next day began at 9:30AM, a time negotiated with the women and the shelter, and two more women came forward wanting to participate. By the end of the first day an additional two women asked to participate in the project, bringing our participant number to eight. Women seemed genuinely interested, willing and eager to participate. Some women had part time jobs, others had adult education classes, and times to meet were negotiated around these commitments.

In other communities, a model of community visits, spending two to three days in each place, return visits and working with individual women, was adopted as the approach to this project. Based on positive responses from women participants we believed that this approach supported interpersonal connections and communication that opened up with women providing opportunities for dialogue and sharing. Participant women were asked to take pictures relating to the primary research question and return to work with team members on their individual Photovoice product. Our approach also resulted in developing individual PowerPoint representations of pictures and captions by each woman participant. It was clear that this was meaningful to the participants and that creating the PowerPoint's served as a means to review the captions and perspectives represented by each image. This approach also led to dialogue between the women and the research team that was engaging and interesting. It helped deepen connections with the participants as it took time to do this work.

Women clearly expressed a desire to participate in the Photovoice work once they heard about the project. There was excitement about seeing the photos downloaded to the computer and working on captions. There was a warmth and genuineness clearly visible when working with different women in talking about their photos, the meaning of these images and the creation of captions. Photos were cut and pasted directly into a word document and team members met with each woman individually to create the product. The product becomes the photos and captions completed by each woman participant in collaboration with a research team member.

Photovoice examples

In order to fully appreciate the experience, for example, of women experiencing homelessness and past struggles with addiction, it is important to share a few slides that highlight this experience.

I'd like to find a better place: There is no room –too close together, have to fold mats, women shower and go early before fights start, clothes, more luggage, have to wipe clean mats –some women leave and don't help. Clothes-dirty and clean –all mixed up, no room. I used to have a place. I worked for two years in a hotel, changed rooms, they kicked me out cause I couldn't pay rent. I lived at my nieces and then moved here (center) in May or June.

Image 2: Storage Room for Personal Belongings at Centre for Northern Families in Yellowknife



My old school: This is a picture of the high school. If I could start over and turn back time I would go to school. We were five brothers and 1 sister. After my Dad died it was hard. I went to school but I (couldn't finish). I wish I could start over and get my education. I could have had a better job-better family life – more support (with my education).

Image 3: A high school in Yellowknife



This old house: This old house is boarded up and there is bush –space around it. It reminds me of my grandpa who built tables and benches. Sometimes we had nothing to eat, no welfare, no flour, no milk. Mom would put up snares for rabbits and ptarmigans.

Image 4: A boarded up house in downtown Yellowknife



A place to hang out: Someone asked me to go drinking this morning [working on Photovoice Project]. I told them I was busy. It's a struggle doing hard drinking. Sometimes I go to the library, go sit, sometimes and have a couple of shots just to get through the day. I try to keep away from drinking. Sometimes people ask me and it's an excuse to go out. Sometimes I can't help it.

Image 5: The Friendship Centre in Yellowknife



A place to go: It hurts, people don't want to learn about others –it hurts –I keep everything inside about my life. Maybe if I see something like that it would help me.

Image 6: The Centre for Northern Families in Yellowknife, NT



Discussion

These images clearly portray the thoughts of women that are deeply personal, reflective of personal struggle and rooted within one's history. When looking at the Photovoice work of each individual and then examining the overall picture of four communities it was clear that homeless women were particularly marginalized and oppressed and often had limited opportunities and resources to change their life circumstances. While supportive resources exist multiple challenges and barriers are also present. The most important aspect of supporting and engaging women in FASD prevention work is a supportive, empowering, non-judgmental approach that addresses fears and stigma on this topic. With FASD prevention embedded as a health topic through this qualitative research project, we were provided with an opportunity to engage more broadly on the topic of health and alcohol use with women in terms of what they were comfortable with sharing. Through meeting women in their home communities it becomes possible to listen deeply to what they have to say and to reflectively engage on health related issues through the images that women provided through Photovoice. As a result of conversations with women in the BOHF project other topics raised by women included fears about harms from past experiences (historical trauma and abuse), violence, lateral violence, poverty, remoteness, isolation, lack of support, and for some women, homelessness. While meeting with the participants in Yellowknife on different occasions over a year, at least three of the women were observed to have black eyes. The cause in each circumstance was explained as homeless women being beat up by other women on the street. While this information is anecdotal to the BOHF research, it stood out as a concern to pay attention to and highlighted concerns about safety for homeless women in the community. The images presented in this paper highlight different social and health problems.

Why is this research important?

This research project is important because it offered women a venue and an opportunity to give voice to their experiences in relation to health and to inform us, from a deeply personal position, about what speaks to them, what has meaning and what is important in their lives in support of health and healing. We see this research as an opportunity to provide women with a space and opportunity to contribute to the discourse on women's health and FASD prevention. This was achieved by informing women about the project, inviting women to participate, providing women with digital cameras to keep, teaching women about using the camera, and engaging with women in the process of talking about their pictures, forming words and captions to express the meaning of the pictures. Appreciating FASD prevention from a specifically Northern lens is a critical issue in raising awareness on this topic. The BOHF project identified the need for FASD prevention discussions and highlighted the need to consider increasing opportunities in the North to have dialogues in relation the use of alcohol as a means to cope with difficult and challenging interpersonal circumstances.

Primary themes emerging from the BOHF project

A complex process of qualitative analysis utilizing Atlas Ti, a qualitative software program, was undertaken in terms of reviewing the images and captions individually and by each community. Images that were presented to members of the research team were clearly reflective of different constructs related to their lived experience. These constructs are both physical and metaphorical/symbolic of a woman's life. This project generated a very large amount of data and information, therefore it is necessary to present what is realistically achievable in one article. Forthcoming articles will present different aspects of this research. The broader representations of recurring themes through data analysis will be provided. In the BOHF the following key themes emerged:

1. *Place* – in terms of where a woman lived and reflective of different stages of life; age in life; identity; challenges such as homelessness, remoteness and isolation.
2. *Family* - having children; connection with relatives – parents, siblings, grandparents, aunts, uncles and cousins; husbands, partners; the role of related and community elders and relations with people in the community.
3. *Environment* – connection with the land, in terms of life situation and life location (time and space in life's journey – troubled spaces); safety and security
4. *Tradition* – linkages to culture: past and present;
5. *Cultural Practices* – country food, hunting, food preparation, gathering, sewing and handicrafts, medicine
6. *Spirituality* – having a spiritual life is deeply connected to tradition, the land and belief in a higher power.
7. *Health* – supports to be healthy; nutrition; access to health care – addiction treatment; support for healing

Reflection on the unique aspects of each community participating in Brightening Our Home Fires Project

There was a lot of excitement generated by this project. The initial support letters from each community, after visits primarily led by Arlene Hache, former Executive Director at the Centre for Northern Families, were critical in moving this project forward. The four communities included Behchokö, Lutsel 'Ke, Ulukhaktok and Yellowknife. These communities represented a great deal of diversity and each had their own unique characteristics and participants. Experiences in each community were distinct, unique for each community, reflective of local context, highlighted the meaning and value placed on family and offered differing viewpoints on culture and health, substance use, community and isolation, the meaning of home, and homelessness

Limitations of the study

This study is important as it represents a new body of work that utilized Photovoice as a means to talk largely about social health with an underlying goal of supporting FASD prevention. Establishing relationships and community connections was a crucial part of this work. This takes time. There were times when trips to two communities were cancelled due to deaths in the community. The time frames around the project and travel were challenging. There is stigma association with talking about FASD and it is hoped that this topic becomes more open as communities become more engaged in prevention work. We recognize that this is a challenging issue to discuss and this study was exploratory in nature. We do not know if women in the project were women who used alcohol during pregnancy and most of the participants had children. We included all women who came to this project because all members of a community are considered critical informants to this work as FASD is an issue that affects whole communities. While this project was focused on adult women, it would be very interesting to work with other community members on this topic.

Conclusions

Engaging in FASD prevention work through the lens of a camera was grounded in the guiding principles that Photovoice was a means to develop and share new knowledge, to develop community connections in the Northwest Territories with Dene and Inuit women, to recognize that women are the best teachers about their health and healing networks and to recognize that a digital camera is a tool to engage in dialogues about health. Photovoice offers a meaningful form of engagement, a new opportunity for learning and a way for women to express themselves in ways that are not solely based on answering questions in a traditional research approach. A final report (Badry, 2012) was written on this research and shared with the First Nations Inuit Health Branch who funded this work.

The benefits of approaching this research through this methodology were almost immediately appreciated when engaging with women participants. The enthusiastic response and interest to this project was positive. A couple of young women spoke about having healthy pregnancies, the positive influence of family in relation to their own health and the challenges related to health for marginalized women who were homeless. There are clearly two distinct groups emerging; women who are homeless, and women who are connected to their communities. While their experiences were different similarities exist about the importance and value of engaging in activities that are related to health and offer connections to tradition and the land.

The most important aspect of supporting and engaging women is a supportive, empowering, non-judgmental approach. Some of the things we learned and that require further reflection about FASD prevention work relate to:

- Addressing fear, stigma, misinformation, discrimination - racism
- Meeting women *where they are at*, with basic needs met first such as housing
- Helping women with related harms especially harms from violence, lateral violence, poverty and homelessness.
- The foundation of health and healing are critical constructs in FASD prevention.
- Engaging in FASD prevention work in the North requires a culturally sensitive approach and a deep focus on the lives, positive and challenging aspects of daily life for women in community.
- *Community connections are forged through presence*. Work needs to be done in communities and requires initial visits, working sessions and follow-up.
- *A woman first perspective* is clearly visible through Photovoice – pictures and captions.
- Women in the North are deeply connected to each other and their community.
- As one elder said, “*We have to be inclusive of the men*” in this work.
- Talking about FASD is a sensitive topic and needs to be carefully and respectfully approached in the North in a community engagement process that is located broadly within a health framework.

Throughout the BOHF research project it was clear that women who maintained strong community and family connections felt greater support and their images portrayed the strength of these connections. Women who were dislocated from place and community through homelessness portrayed deeper inter-personal struggles while recognizing and identifying more readily their struggles with addiction.

This project was ultimately about FASD prevention, yet taking an approach focused on health and healing was critical for engagement with women participants. It must be noted that discussion on FASD prevention took place at the outset of this work through two processes. The first discussion came about through visiting with communities and introducing the *Brightening Our Home Fires Project*. The *second discussion* came about through the process of signing informed consents, as these documents were very detailed in terms of the focus of the research on FASD prevention. While enthusiasm was evident about doing the Photovoice work there was some trepidation on the part of a few participants about the focus on FASD and one woman reflected that she was uncertain about what she was getting into. The research question was: *What does health and healing look like for you in your community?* The question itself offered a place for women to reflect on their lives in new ways. This research highlighted both the struggle with addressing FASD and the benefit of approaching the topic from a lens focused on women's health. We hope that this work will contribute to that growing body of literature and increasing knowledge base and awareness of FASD in Northern Canada.

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Appendix 1

List of Images

Image 1: Digital Camera and Hand Made Camera Case

Image 2: Storage Room for Personal Belongings at Centre for Northern Families in Yellowknife

Image 3: A high school in Yellowknife

Image 4: A boarded up house in downtown Yellowknife

Image 5: The Friendship Centre in Yellowknife

Image 6: The Centre for Northern Families in Yellowknife, NT

An Interdisciplinary Journal

Honoring the Voices, Perspectives and Knowledges of First Peoples through Research, Critical Analyses, Stories, Standpoints and Media Reviews

Healing through Photography – A reflection on the Brightening Our Home Fires Project in the remote hamlet of Ulukhaktok, Northwest Territories

Annie Goose¹ and Dorothy Badry²

¹ Community Liaison, Translator, Project Participant, Ulukhaktok, Northwest Territories

² PhD, RSW, Faculty of Social Work, University of Calgary, Calgary, Alberta, Canada.

Corresponding author: Dorothy Badry, badry@ucalgary.ca

Abstract

This creative piece of work and writing showcases the work of a woman participant from the community of Ulukhaktok in the Northwest Territories (NT). Ulukhaktok is located on Victoria Island above the Arctic Circle. This community shares land with its neighbors in Cambridge Bay, Nunavut; located on the north end of the island. The hamlet of Ulukhaktok, NT and many small, remote and isolated places in the territories reflect a rich cultural Inuit heritage in regions, settlement areas and communities. There is a deep sense of interconnectedness within the North in a vast landscape that is known as home to Inuit culture. The purpose of the Brightening Our Home Fires Project (BOHF) was to work in four communities in the NT on a project related to prevention of Fetal Alcohol Spectrum Disorder in the north. A co-researcher living in the NT suggested the community of Ulukhaktok (formerly known as Holman Island, NT) as a place to visit and invite participation. Annie Goose supported this project through participation, acted as a translator and supported us by facilitating meetings within the community. Annie is the primary author of the work shared in this paper. It was my privilege to share in this work and support the knowledge development and exchange that deeply highlights the impact of the Brightening Our Home Fires Project. This work speaks to the possibility of Photovoice in giving voice to unheard experiences in a creative and innovative way on complex areas of health. This article will be of interest to people who are interested in topics such as Northern Canada, qualitative research, women's perspectives on health and healing, and those interested in Photovoice as a methodology.

Authors' Note: This paper is part of the Brightening Our Home Fires project. It is the third in a series of three articles in this journal: 1) An Examination of Three Key Factors Alcohol, Trauma and Child Welfare: Fetal Alcohol Spectrum Disorder and the Northwest Territories of Canada, Brightening Our Home Fires; 2) An Exploratory Study on the Use of Photovoice as a Method for Approaching FASD Prevention in the Northwest Territories; and 3) Healing through Photography – A Reflection on the

Brightening Our Home Fires Project in the Remote Hamlet of Ulukhaktok, Northwest Territories. Together these three articles provide a comprehensive introduction and overview of this project that took place in the NT from 2011-2012. These are the first publications on this research. This project received funding from the First Nations and Inuit Health Branch, ethics approval from the Conjoint Faculties Research Ethics Board at the University of Calgary and a research license from the Aurora Research Institute after a process of community consultation with different communities engaged in this project. These papers are of interest to researchers, practitioners and educators in the north. Names and images are used with permission of the individuals. All the images in this article were taken by Annie Goose. Special thanks to Laverna Klengenber for her identification of this project as Healing through Photography, a title that truly resonates with the work of the Brightening Our Home Fires Project.

Introduction

On our first trip to Ulukhaktok in January, 2011, Arlene and I remarked that it was mighty cold and dark. We went to the Arctic Char Inn and were the only guests at the time. After getting settled we had a meeting in the Helen Kalvak Community Centre. We met with a number of women with children who were eager to hear about the project, to learn about digital photography and sign consents. One of the key issues we recognized at the outset was that just talking about Fetal Alcohol Spectrum Disorder (FASD) prevention, was not going to be a welcome approach in any community. We considered this question deeply as a research team long before going to any of the four participating communities. We perceived that talking about FASD prevention would be a barrier to participating in this project that is, at its essence, about women's health. This approach was informed by our participation as part of the Network Action Team on Women's Social Determinants of Health under the umbrella of the Canada FASD Research Network. Our decided focus after much discussion was the question: *What does health and healing look like for you in your community?* In response to this question a series of photographs were returned to members of the research team on sight and a discussion took place to reflecting the words and images and create a Power point. The Photovoice project, created by Annie Goose in response to this question is the highlight of this article.

Brief review of methodology

The BOHF project used Photovoice as a primary methodology for this qualitative research project. Photovoice is a Participatory Action Research (PAR) approach. An ethics certificate was granted by the University of Calgary and a research license from the Aurora Research Institute approved a research license (a requirement for all research projects in the Northwest Territories). A letter of support was received from the mayor of this hamlet, an ethics certificate and license was granted and the work of one woman participant is highlighted in this paper. While appreciating this project was on FASD prevention, it was clear to the researchers that a holistic approach that considered health and healing as foremost offered a beginning place.

With this in mind we invited community members who wished to participate to an information session and we offered a brief workshop on digital photography. Informed consents were carefully reviewed and translated as required for women participants involved in the project. Brief discussions took place on FASD and some very interesting dialogue occurred. We did not want the term FASD prevention to serve as a barrier to participation in this project. We emphasized a focus on health and healing and indicated that this was an important construct for this research. Why did we use this approach? We used this approach because it is respectful, culturally sensitive and it reaches out to women where they are at in their lives. It also provided an opportunity for women to explore issues of health through the window of photography that is completely centered on the voices of women choosing to engage in the project. The title of this article was voiced by Annie's daughter, who stated when reviewing and selecting her photographs for inclusion in the project: *"I never thought about healing through photography!"* The women participants in this project and in this community were highly engaged and interested in the work and were provided DVDs that included a Power point presentation of the work.

Acknowledgements

As a researcher it was a privilege to spend time in the community of Ulukhaktok, to experience the warm welcome of the people, to converse with women who ranged in age from young mothers to elders and to simply spend time on the land. I have made three visits to this community. The first time I actually saw the land without snow was at the end of June and in early July 2012. I participated in a number of community events such as a feast and research meeting held on Food Security in the community during this visit and met many residents of the community. I attended cookouts and went fishing and boating I am particularly appreciative of the care and kindness of Annie and the women of this community who were willing to share their experiences, to take photographs and express some of their deepest thoughts around health issues, and to occasionally talk about some of the challenges experienced by women of the north, in one of the harshest environmental climates in the world.

While these images and words belong to Annie Goose, I simply express my gratitude for this experience and knowledge that is being disseminated and developed because of the BOHF project. The support of the First Nations and Inuit Health Branch (FNIHB) made this work possible and their support of the BOHF project is deeply appreciated. While the work in this article represents the viewpoints of one woman, I can fairly state that the work included here is representative of a spirit of caring and concern regarding issues of health, and those transformative experiences of healing that take place as one moves along the continuum of life. This work should be considered in light of issues regarding women's health in the North. These representations are art – the images and words appear to intermingle to present a holistic portrait and viewpoint that represents both health and healing. I was constantly amazed at the reflections that came forth from women engaged in the Photovoice process. In essence, the question of what health and healing looks like in a remote, northern community portrayed a great deal about life as experienced by women in the north. The depth of insight that emerged through taking pictures, talking about the pictures, and creating captions opened many doors. Photovoice provides a venue for talking about complex health issues in a non-threatening way. Taking pictures and reviewing images offers a space from which personal meaning and reflection or dialogue can occur in relation to complex health topics.

Dorothy Badry

Image 1 – Map of the Northwest Territories



Image Source: <http://www.aadnc-aandc.gc.ca/eng/1100100027749/1100100027753>

Annie Goose – In my words - My journey – My life



What does health and healing look like for you in your community?



My Home

My healing came from a place of no return. It was a very difficult beginning. As time went by it became easier to work with. As a young child, I lost my inner child stemming from abuse which I did not realize was just that. As years went by I raised my family with what I had. I realize today I put my family through a lot. I didn't know that I could do something about it at the time. I think I was just surviving in those days.



My family – enjoying the simple things in life

Today I am honored that my own family has found in their own way to forgive me. My bonding with them is more genuine than ever before. And, we are the best of friends, my boys and my daughters. We can share, and laugh and be real with each other. That gave me great inspiration to carry on with my own life.



My Mother – Agnes Nigiyok

My great mentor was my adoptive mother who was the only mother I know. But, later in years I became closer to my biological family. I believe very strongly abuse divides, your home, your relations, your community, and so on. And, the only person that can do something about it is you. I did just that. I began my healing journey in 1992. It was never easy.



I have good mentors

I have good mentors. One of them was my mother Nigiyok. She taught me to appreciate anything that came by as a gift whether it be a fish she caught or plants from the land that she harvested because it was her way of giving her best in bringing to us children, my brother, myself; the best she had. There were days that she had to chisel through 6 feet of ice to fish just so that we can have broth and a bit of meat – a meal that day.



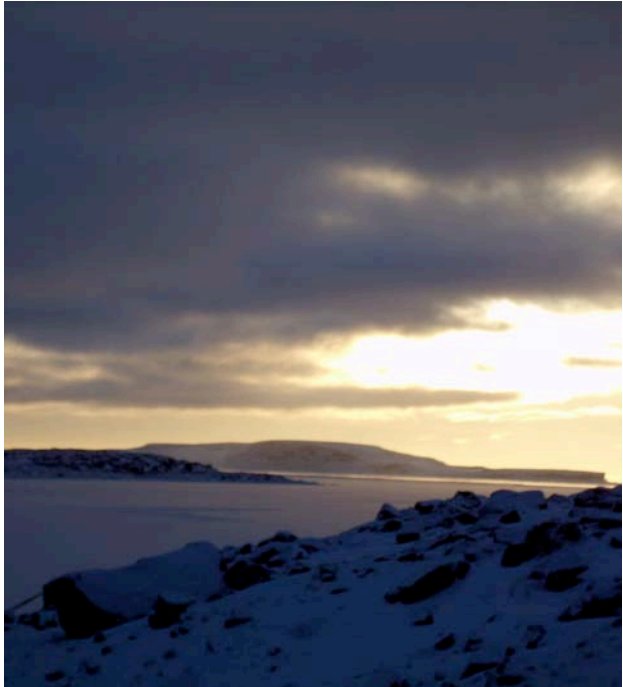
Stones and Tools – A Reflection for my Life

These are the stones I have gathered from my travel and my community. One of my favorite places is the Arctic Ocean along the shore where I pick most of my stones. These are the stones I gather from my travel and my community. Many of these stones are from different oceans the four corners of the oceans of the world. You lose friends who you thought were your friends. My coping mechanism was alcohol. It took many years for me to deal with that. It took three treatment programs and family support, friends and community and I am very grateful for that. Today, I have been sober 19 years with many achievements, some mistakes and most of all a sense of belonging.

I feel connected to the stones as part of my life journey - It is in all my travels to the four different oceans – Nunavut, Nunatsiavut, Pacific and the Beaufort Sea that a lot of my healing has come together whether it is walking the sea wall or just the scenery along the Arctic Ocean – in the freshness of the Arctic Ocean air and every stone seemed to tell its story whether its flat round or rugged of my own life story. The different shapes, color, size, whether they were round or rugged reflected a part of me and how I progressed in my own healing.

Handicraft – Rocks - My mom’s handicraft of clothing she made was appreciated by us and that is where I learned to do my best for my family and myself. She was a hard worker and displayed her faith by doing rather than by talking. In my own work and healing, I model what I have learned throughout my life. To share with care with those around me, my family, my community and anyone else.





Today I love my world

Today I love my world. Thankful to wake up and grateful to appreciate my day with my family and my grandchildren and great grandchildren. My faith has a lot to do with my daily life. I have learned to take back my power which I lost along the way. It was always mine. I believe many times you don't have to talk very much, but you model your own healing along the way because everybody has their own way. Healing begins by saying I want my power back and forgiveness has a lot to do with the process. And, the greater part of your healing is your humbling attitude.



My work – Part of my therapy is through my handicrafts which are very relaxing in creating the colors and the choice of colors – the colors I choose reflect my healing and how far I have come. I have a need to see the mistakes I make sometimes in my own life and reflect on how on my own life can be through my creations. Sometimes it's so easy to go back and see the mistakes in life and as I do my creations through my crafts it brings me right back up. I do not stay too long in my own negative world I used to be in, because it was back in my lifetime, the time of darkness and pain as I do my handicrafts it helps me to relax and take pride in my work and be real in my own healing journey. As I grow older and progress in life I begin to know my own need to model and not so much speak it or



The Land – is my place of therapy, picturesque scenery, flowers, the stones, the rocks, the plants, animals, birds, ocean mammals all have a place in my own life. There was time in my own life that I did not know how to properly prepare these things as a young mother, and over time I learned these skills, and how to store away dry, frozen meat and the land has a way for my own life. I feel free, energy – you can gather energy wide as your arms, high as the sky and as deep as the ocean for your own life. If I am in the tree-line country I improvise – take what I can and leave the rest.

In summary

Photovoice is a very safe passage for one to express their selves. Our words and pictures convey more about our inner being and support healing more than I realized. Taking pictures can reflect everyday reality and contribute to healing your inner being. This experiencing gives you an enjoyment – just being true to yourself and those around you. There are moments that you never realize you see until you take a picture and then you see it – differently. Photovoice through images and true colors offers inner peace and enjoyment of moments in your life that you never thought were important.

Annie Goose – June 26, 2012, Ulukhakto



***Journal on Developmental Disabilities* special issue on FASD**

The *First Peoples Child & Family Review* was honored to partner with the *Journal on Developmental Disabilities* (JoDD) to produce sister issues on Fetal Alcohol Spectrum Disorder. The following are abstracts from the JoDD's upcoming issue.

Meeting expectations

Stephen Clifford

Abstract

The adoptive father of a young man with FASD tells the story of his family's journey towards getting a diagnosis and how this helped him to better understand his son. He describes the struggles and the joys the family experienced along the way and how the knowledge and understanding that followed the diagnosis enabled them to adjust their expectations in order to improve the quality of life of their son and the whole family.

Determinants of drinking during pregnancy and lifespan outcomes for individuals with Fetal Alcohol Spectrum Disorder

Kelly Coons

Abstract

Fetal Alcohol Spectrum Disorder (FASD) has been identified as a major public health concern. However, limited research has used longitudinal data to track the developmental life course of these individuals. Furthermore, women who drink during pregnancy are not a homogenous group. Concerns regarding drinking behaviours in women who are or could become pregnant are therefore of great concern. The aim of this paper is to provide an overview of a number of risk factors that contribute to a woman's drinking during pregnancy and FASD risk, as well as the subsequent lifespan outcomes that occur in individuals with FASD.

Media review: *Defendor*

Bruce Edwards

Abstract

In this review of the Canadian film *Defendor*, a story of a man with FASD who believes himself to be a superhero, the author turns to interviews with the film's director and star (Woody Harrelson), as well as other media reviews of the film, to explore both the expectations for the film and how it has been received by film critics and movie-goers. The author was a clinician in a diagnostic FASD clinic who met with Harrelson as he prepared for the role. Speaking to Harrelson's efforts to do justice to his portrayal, Edwards concludes that the film delivers a hopeful message about FASD. He notes that the film makes clear the struggles typically experienced by someone with FASD but suggests that it also demonstrates how a person with FASD can make positive difference in the world.

Why *can't* we be superheroes?: Researchers with and without intellectual and developmental disabilities talk about *Defendor*

Ann Fudge Schormans, Rebecca Renwick, Denzil Barker, Emanuel Chasi, Bobby Smith, Leslie McWilliam, Sorin Uta, Jory Gruber & Lauren Saks

Abstract

As part of a research project exploring cinematic representations of people with intellectual and developmental disabilities (IDD), a group of researchers comprised of people with and without IDD reviewed the Canadian film *Defendor*. The group generally liked this film in which the main character, Arthur, is a man with FASD. What was most interesting to us was that the Arthur, like Superman and Batman, was a 'regular guy' during the day but a 'superhero' by night – fighting crime and avenging the death of his mother. The purpose of the research project, however, was to explore how people with IDD are portrayed in Hollywood film and the messages that non-disabled audiences would take from a movie about persons with IDD. It is still rare to see films in which the lead character has an IDD, even rarer to see a person with an IDD portrayed as a superhero. In this review, we talk about whether this portrayal worked to give audiences an alternative way of understanding persons with FASD or reinforced long-standing negative beliefs and attitudes.

The complexities of caring for individuals with FASD: The perspective of mothers

Debbie Michaud & Valerie Temple

Abstract

Fetal Alcohol Spectrum Disorder (FASD) may be associated with a variety of challenges including developmental disabilities, hyperactivity, attention and impulse control problems, language delays, and social skills deficits. These problems can lead to “secondary disabilities” such as mental health issues, academic and vocational failure, substance abuse, and interactions with the justice system. Parents of children with FASD often struggle with the overwhelming demands of supporting their children. In this study Participatory Action Research was used to address two questions: What are the experiences of parents caring for children with FASD? and What do parents believe their families and children with FASD need to ensure good outcomes? The study included five mothers (either adoptive, foster or biological) of individuals with FASD. In their discussions participants described using unconventional parenting techniques and shared their guilt at being unable to meet the complex needs of their children. They expressed fear for the future as their children moved into adulthood. They discussed the need for lifelong parenting and for smoother transitions between children’s and adult services. Participants felt empowered knowing that they were not alone in their challenges as parents.

Ontario educators and Fetal Alcohol Spectrum Disorders: A training, resource, and evaluation project

Gal I. Koren, Alexander Sadowski, Talya Scolnik

Abstract

Appropriate school-based support is a critical piece in improving life-outcomes for all children, particularly those affected by Fetal Alcohol Spectrum Disorders (FASD). A 2010 needs assessment highlighted a lack of knowledge about FASD among Toronto public school educators. This paper reports on a new education resource and professional development session on FASD targeting schools around Ontario. Training and resource support was provided to 829 Ontario school staff with varying professional backgrounds and experience during the 2011/12 academic year. The training initiatives were evaluated through participant completion of questionnaires, and descriptive statistics were calculated. Participants were employed across eight school boards which represented enrollment in excess of 575,000 students, or an estimated enrollment of 5,750 (1%) FASD affected children. This initiative was the first learning session on FASD for most participants (75%), and 79% stated that both their own and colleagues’ involvement in this initiative will help future job performance. Ninety-nine percent of respondents reported that the FASD resource serves an important function, may be a useful tool for educators, and that they would recommend it to colleagues. Finally, 93% reported that this initiative led to increased knowledge and confidence in the topic of FASD. This initiative demonstrates that school professionals benefit from resource support and training about FASD, and the Motherisk FASD Clinic module provides a solid, evidence-based, and cost-effective framework for the introduction and continued support on FASD in Ontario schools.

A mother's plea for her child with FASD

Kathy Moreland Layte

Abstract

This poem, written by an adoptive parent, is a plea for all people to understand the needs and challenges of children born with FASD. It speaks of FASD as an often invisible disability that is not well recognized or supported, and the hardships this can bring for the individual and their family. This lack of understanding and commitment of resources by the broader community can lead to the tragedy of a child with a broken spirit.

Environmental scan of programs for Fetal Alcohol Spectrum Disorder (FASD) in Eastern Ontario

Danielle Naumann, James Redmond, Holly Smith

Abstract

FASD is a leading cause of developmental disability in Canadian children. The majority of Canadians with FASD are not identified: FASD is diagnosed in less than 1% of Canadians, when it may occur in as high as 2-5% of the school-aged population. This discrepancy is due in part to a lack of harmonized policy and service coordination at national and provincial levels. Failure to provide appropriate interventions for individuals with FASD results in the development of debilitating secondary effects that impact individuals, families and communities. Ontario is the most populated Canadian province with an emerging provincial strategy for FASD that is challenged by additional barriers to effective service provision and utilization. The eastern Ontario region represents a population of 3 million residents that are particularly underserved. This environmental scan used formal and informal sources to explore, summarize, and map out current services for FASD in order to present a comprehensive review of service accessibility. The results inform residents, policy makers, service providers, and program developers on the scope and nature of services for FASD located in the eastern Ontario region in 2012.

My baby's mother

Elizabeth Russell

Abstract

Written by a foster parent, this poem speaks to the possible thoughts and feelings of a pregnant woman as she looks in the mirror and thinks of her unborn child. Though she loves the child, she still watches herself fill a glass over and over, drinking despite this love. It is a poignant depiction of the conflicting emotions a woman might experience in pregnancy and addiction.

“A Window of Opportunity”: The proposed inclusion of FASD in the DSM-V

James Sanders

Abstract

FASD is a lifelong disability resulting in clinically significant dysfunction that frequently leads to adverse life outcomes for those affected. Yet, FASD diagnoses are often insufficient to obtain the services and supports that clients need to prevent these secondary disabilities. A Diagnostic and Statistical Manual of Mental Disorders (DSM) diagnosis is widely considered a gateway to treatment and support. Efforts to include FASD in the DSM appear to have begun in the last 10 years. A review of these efforts suggests that reimbursement issues and the enabling of services have been much of the impetus for promoting in the inclusion of FASD in the DSM. Criteria for a FASD-related condition, Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE), have been proposed in section III of the DSM-V as a condition that requires further research. Criteria include the presence of neurocognitive impairment, impairment in self-regulation, deficits in adaptive functioning, and confirmation of more than minimal alcohol exposure any time during gestation. This is a departure from current FASD diagnostic guidelines, which assess growth restriction and facial features in addition to central nervous system dysfunction and prenatal alcohol confirmation.

“I’m hoping, I’m hoping...”: Thoughts about the future from families of children with autism or FASD in Ontario

Shelley L. Watson, Stephanie A. Hayes, Elisa Radford-Paz, and Kelly D. Coons

Abstract

Applying hope theory, this mixed methods study compared the experiences of families raising children with FASD with families of children with Autism and specifically their thoughts about their children’s futures. Participants filled out two questionnaires, the Parenting Stress Index- Short Form and the Hope Scale. They also participated in in-depth semi-structured interviews. Questionnaire responses revealed that parents of both disability types have several fears for the future, but no significant differences were found between participant groups on the quantitative measures. Although parents of children with both disability types discussed similar concerns for the future in interviews: anxieties regarding level of independence, educational and vocational concerns, and fear of harm, there were qualitative differences in their anxieties. While recognizing that life may be harder, families of children with Autism were hopeful when they spoke about future possibilities; that their children would be fully independent, educated, meaningfully employed, and married with children. In contrast, families of children with FASD recognized their lack of hope for their child’s future, citing difficulties establishing independent living, education, employment, and significant positive relationships with peers and/or partners. Parents of children with FASD also accepted that life might include jail, teen pregnancy, and other adversity. Results are discussed with reference to community awareness and supports available for families of children with Autism and FASD. The importance of mixed methods research is also highlighted.

Fetal Alcohol Spectrum Disorder: Exploratory investigation of services and interventions for adults

Jessica A. Wheeler, Kara A. Kenney, Valerie Temple

Abstract

The purpose of this literature review was to examine published information regarding interventions for adults with Fetal Alcohol Spectrum Disorder (FASD). The review was limited to articles that included an experimental design (i.e., pre-post measures) to ensure a focus on evidence-based interventions. Due to the limited amount of research available for the adult population, articles included here are primarily interventions aimed at children and adolescents. These were grouped into the following categories: family-centered, cognitive, adaptive training, and community-based interventions. A review of the “Best Practices” document produced by Health Canada (2000) is also presented. Limitations, efficaciousness of practices, and future directions are also addressed with regard to adult services for FASD based on this literature.

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