

## Capturing the Experiences of FASD Prevention Workers Through Quilting

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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.

## An Examination of Three Key Factors: Alcohol, Trauma and Child Welfare: FASD and the Northwest Territories of Canada

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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 K'e. 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.

## An Exploratory Study on the Use of Photovoice as a Method for Approaching FASD Prevention in the Northwest Territories

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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 K'e, 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.

## Bound by the Clock: The Experiences of Youth with FASD Transitioning to Adulthood from Child Welfare Care

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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.

## Parents with FASD in the Child Protection Systems: Issues for Parenting Capacity Assessments

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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.

## Healing Through Photography – A Reflection on the Brightening Our Home Fires Project in the Remote Hamlet of Ulukhaktok, Northwest Territories

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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 sug-

gested 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.

## Alcohol is a Great Destroyer: A Call for Insight on Ceremonial Approaches for Coping with FASD

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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."

## Voices from the Community: Developing Effective Community Programs to Support Pregnant and Early Parenting Women Who Use Alcohol and Other Substances

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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 Kagiikwe 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.

## Resilience and Enculturation: Strengths Among Young Offenders with FASD

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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 encul-

turation 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.

## Voices of Women Living with FASD: Perspectives on Promising Approaches in Substance Use Treatment, Programs and Care

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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.

## FASD Among Aboriginal Children Under Six Years of Age and Living off Reserve

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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.

## A Social Work Student's Developing Understanding of FASD from Medical and Social Perspectives and Implications for Practice

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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.

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