Looking After Each Other: A Dignity Promotion Research Project for FASD

This information sheet has been prepared so that we can provide information about our study with a variety of stakeholders that we hope will be interested in becoming partners in our research

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Study Background: Although historic and current efforts to prevent Fetal Alcohol Spectrum Disorder (FASD) have been well intentioned, such efforts have inadvertently stigmatized this lifelong disorder. Misunderstandings about FASD and alcohol use in pregnancy have lead to negative impacts on children, adults, families, and communities. Mothers who drink during pregnancy are labeled as 'bad mothers' and 'beyond hope'. Children diagnosed with FASD are seen as 'damaged at birth', 'troublemakers', 'dropouts', and a 'societal problem'. Because of this stigma, those with FASD experience multiple, intersecting layers of discrimination. Stigma is intensified further by discrimination based on gender, race, disability, social class bias, poverty, and/or a legacy of historical traumas experienced by Indigenous peoples. The research team was formed as part of Looking After Each Other: A dignity promotion project. This project aligns with the goals of the Provincial FASD Strategy and is strongly supported by Healthy Child Manitoba.

Study Purpose: To identify and ameliorate stigma and discrimination, our partnership embraces a rights-based framework in accordance with international declarations/conventions on human rights, disability rights, children's rights, and Indigenous peoples' rights, all of which promote human dignity and require dignity work to achieve them (e.g., courtesy, recognition, acceptance, generosity, presence, love, advocacy, leveling and empowerment). The over-arching purpose of our partnership is to build crosssector knowledge and understanding of dignity-promoting approaches for children, adults, families and communities impacted by FASD.



Study Objectives:

- 1) To map the systemic, discursive pathways needed to promote the dignity of those impacted by FASD;
- 2) To uncover the ways in which trauma-informed approaches can promote that
- 3) To reveal the ways in which different cultural beliefs can promote that dignity;
- 4) To explore how child-family-centred services can promote that dignity; and
- 5) To understand how community inclusive/mobilization approaches can overcome stigma and promote dignity.



Participants and Methods: This is a Community Based Participatory Research (CBPR) project in which we learn together with communities, families, individuals and organizations. Any of the following list could participate in this project: youth and adults with FASD, parents/ caregivers and family members of individuals with FASD, youth and adults connected to addiction and other services, Indigenous Elders, service providers, and community members. A variety of quantitative and qualitative methods could be utilized to meet the objectives of the study:

Surveys:

A survey project will provide critical information on perceived stigma and discrimination, or alternatively perceived dignity promotion concerning individuals impacted by FASD and associated health conditions and behaviours. Survey results will guide interventions to decrease stigma and promote dignity.

Focus groups:

Focus group participants will be asked questions on how best to promote the dignity (e.g., pride) of those people impacted by FASD, factors in the social context that influence the occurrence and attitudes toward FASD, and barriers to services, and solutions to overcome these barriers and improve services.

Elders discussion

circles: Indigenous Elders will be recruited to participate in an Elders discussion circle during which they will be asked some questions on how best to promote the dignity (e.g., pride) of those people impacted by FASD

Digital story activity:

A digital story is a way people express and share thoughts and ideas about a specific topic. A digital story can be made from a range of audio (voice and pictures or drawings. A critical part is of a Digital Story is script/story written by participants that explains what the digital story is about.

music) and visual elements such as

research team member will ask questions that facilitate thinking about FASD and dignity promotion, knowledge of or experience with stigma and discrimination, barriers to services, and solutions to overcome barriers. These questions will guide the participant in developing an art work that shows ways to promote the dignity of those impacted by FASD.

Photo voice activity: Photo voice is a research activity that uses photos and voice to document and reflect a particular issue, concern or need. Participants will be asked to express their points of view or represent their community by photographing scenes that highlight research themes from a set of research questions. These questions will help guide participants in selecting **Public** scenes or objects to photograph.

community cafes: We will hold public community cafes open to the public to attend in community settings. These cafes are intended to raise awareness about

Arts

based

activity: Arts-

based activities

involve developing an

art project (e.g., drawing,

painting, colouring, sculpting)

with other people who are also

doing the activity and are a way

people express and share thoughts

and ideas about a specific topic. A

FASD, stigma and discrimination, and dignity promoting ways. These cafes are designed to facilitate discussion to show different ways a community can successfully work with families impacted by

interviews: Openended interviews will include questions on the participant's background/demographic information, perspectives of dignity promotion, knowledge of or experience with stigma and discrimination, experiences of trauma, barriers to services, and solutions to overcome these barriers and improve

Open-

ended

services.

Ethical Considerations: An ethics application for the proposed research has been submitted to and approved by the University of Manitoba Health Research Ethics Board. In addition, we will review the OCAP principles in the case of First Nations communities.

FASD

Would You Like More Information? Please feel free to contact any of the research team members if your organization, community, nation or group is interested in more information about the project.

