#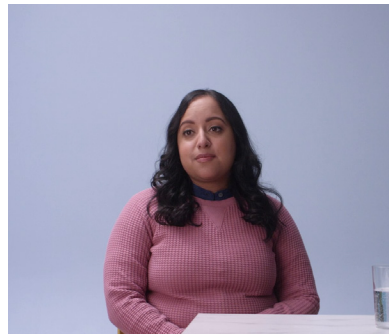 United Families for Our Future Project: An Initiative to Increase Public Awareness in Pregnancy and FASD and Prevent the Use of Alcohol in Pregnancy

YWCA Metro Vancouver Toolkit

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Acknowledgements

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Overview

About the YWCA FASD Prevention Initiative

YWCA Metro Vancouver worked in collaboration with individuals with lived experience and professionals knowledgeable of Fetal Alcohol Spectrum Disorder (FASD), as well as a program evaluator, to develop the *United Families for Our Future* (UFFOF) FASD project.

The UFFOF FASD project was a community-centered project, guided by the voices of individuals with lived experience and those knowledgeable of FASD. The project sought to shift and expand public dialogue on FASD through the creation of a resource that reframes the perception of FASD and includes messaging that addresses underlying stigmas associated with FASD. Together, this group was guided by the principles to:

- Consult subject matter experts at every step

- Ensure messaging always conveys that FASD is a spectrum and needs are different for everyone

- Examine the work through the following lenses: strengths-based, equity, social justice, trauma informed, people centered

- Have messages that are respectful, hopeful and non-triggering

Social Determinants of FASD

Stigmas associated with FASD have been harmful and fail to acknowledge the social determinants of prenatal alcohol exposure. Social determinants of FASD can include: a lack of knowledge one is pregnant; not knowing the impact of alcohol exposure on fetal development; inconsistent messaging on the impact of alcohol on fetal development; lack of access to supports; and a history of trauma or difficulty coping with experiences of trauma (see the Appendices for additional details on the social determinants of FASD).

The UFFOF FASD project was also guided by the following :

- **Trauma informed approach:** acknowledgement of past and current traumas, while creating safe environments and avoiding re-traumatization.

- **Evidence-based and results-driven approach:** findings that are grounded in meaningful data and indicators.

- **Cultural sensitivity:** acknowledgement of cultural contexts and values in relation to health.

- **Multi-sectoral and multi-agency collaborative approach:** various sectors were engaged throughout the duration of this project.

- **Health equity lens:** the design, delivery and evaluation of the UFFOF FASD project was mindful of sex, gender, age, education, language, culture, geography and income.

Project Process

The UFFOF FASD Project was implemented in three main phases:
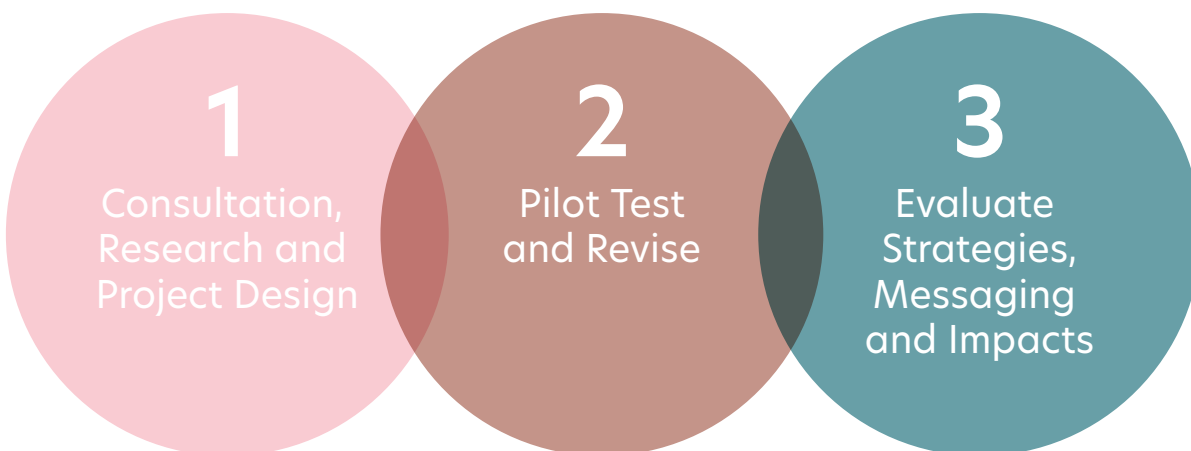
Consultation and research were completed to inform potential resource design and messaging. Once the resource was developed, it was pilot tested and adjusted based on feedback. The last step is to evaluate the initiatives strategies and impact.

The Prevention Resource: The FASD Dictionary

The purpose of the FASD Dictionary is to provide information, resources and access to supports in order to help combat stigma and reduce the prevalence of FASD.

The online FASD Dictionary is comprised of 26 definitions related to FASD, of which five definitions include 30-second videos that explain one "letter" each.

Click the image below to access the FASD Dictionary.

A Toolkit for FASD Prevention Initiatives

Purpose of Toolkit

The purpose of this toolkit is to support other organizations in Canada to replicate the process taken by YWCA Metro Vancouver for developing a meaningful resource to build awareness of reducing alcohol use during pregnancy. This toolkit provides lessons learned and best practices for a process that addresses the underlying stigma associated with FASD using a community driven approach.

Who Can Use the Toolkit?

This toolkit is designed for anyone that would like to create an FASD prevention initiative that involves individuals with lived experience and community voice. This toolkit was developed with grassroots organizations in mind, as YWCA Metro Vancouver reflects their learnings. Potential audience includes, but are not limited to:

- Individuals with Lived Experience
- Non-Profit Organizations
- Friendship Centres
- Community Programs
- Program Coordinators or Managers
- Youth and Elders Groups

The Toolkit is organized into the following sections:

1. How can the Toolkit be Used?
2. Community Engagement
3. How to Approach this Work
4. Project Design and Delivery
5. Evaluation
6. Lessons Learned from the UFFOF FASD Project

TOOLKIT

1. How Can the Toolkit Be Used?

i The toolkit can be used by organizations who are looking for support in developing resources related to FASD. This toolkit can also be used to spark ideas for awareness or resource building in the future.

2. Community Engagement

This section explores all levels of engagement in the development of FASD resources or can be used for general resource development to ensure that a community driven approach is used.

Engaging the Community for Direction and Priorities

Before you consider what resources to develop, it is important to engage the community right from the beginning, particularly those with lived experience.

Ensure that a proper needs assessment takes place so that community voice and needs are prioritized.

To engage community, potential steps include speaking with community members and local service providers.

Community partners can support with:

- Coming up with ideas
- Facilitation of community conferences
- Engaging community
- Learning from their experiences in this work
  - Supporting with education as a way to create a baseline of knowledge for all stakeholders involved in the project
- Create a shared language, including definitions and principles that are going to guide the work

When you connect with community members and organizations, let them know why you are reaching out to them.

Questions You Can Ask Community

When you connect with community members and organizations, let them know why you are reaching out to them (i.e., the purpose of your proposed initiative). Potential questions you could ask include:

- *What priorities do you see for FASD in your community?*
- *How would you like to be involved in this FASD project? Do you have capacity to engage fully in this project?*
- *How would you like to be involved in the development of the FASD resource?*
- *What are gaps that you see in resources related to FASD awareness building?*
- *What resources would be beneficial for pregnant individuals in your community?*
- *Where do individuals access FASD related resources in your community?*
- *Are there barriers to accessing FASD resources in your community?*

Ways You Can Engage Community

Engaging the community can take many forms and can include both formal and informal exchanges. It is important to consider the ways in which the community wants to engage with the project, which could be your first question to ask.

The list below includes ideas for formal and informal engagement.

Informal:

- ☐ Phone calls
- ☐ Meet and greets with individuals
- ☐ Feedback from friends or known colleagues and known experts
- ☐ Connecting with people through word of mouth
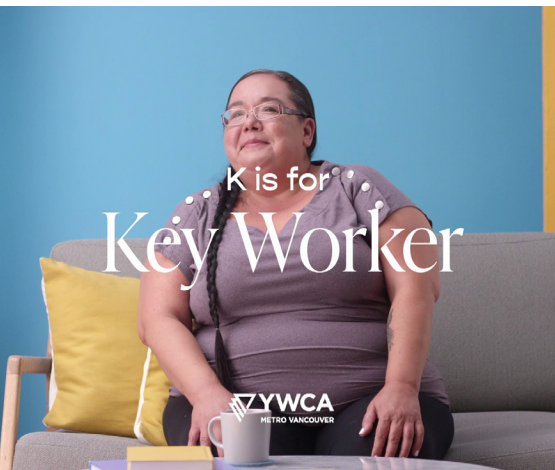
Formal:

- ☐ Surveys
- ☐ Interviews
- ☐ Focus groups
- ☐ Advisory committee
- ☐ Working groups
- ☐ Lunch and learns
- ☐ Conferences/events

Compensate People Who Contribute

When asking people to provide input into the creation and direction of your project, ensure they are compensated appropriately. Consider providing honorariums, food, and travel support if needed.

While many people who choose to engage in co-creating a project or providing direction are already passionate about the topic, consider including creative activities to support creative thinking. Activities could include:

- ☐ Painting
- ☐ Play-doh
- ☐ Clay
- ☐ Beading
- ☐ Colouring

Community engagement should occur at all stages of the initiative.

Community engagement should occur at all stages of the initiative.

If you don't have time to engage with community before you start resource development, you can begin with the following:

- ☐ Engaging with partners, staff, and other organizations to understand the needs they hear from their clients
- ☐ Reflect input from the above and adjust the resource as needed

It is important that once consultation with community partners takes place, that stakeholders engaged in the project establish who is managing the project (timelines, deliverables, etc.), clear roles and responsibilities of everyone engaged, and ensuring that all stakeholders understand the priorities and direction of the project.

Tips for Planning Community Conferences

Community conferences can support with engaging the community and are a great way to bring individuals in a region together to get to know each other, understand pressing needs, brainstorm ideas, and create a networking opportunity. It is important to understand and be mindful of who should be invited to these sessions to ensure that a safe space is created. Below includes a list of tips for planning a community conference:

- ✓ Plan an introductory meeting with the internal team to discuss the community members that need to be involved in the resource development

    - Contact community members identified and schedule a time for the conference based on availability

    - Connect with community members to see if there is anyone missing from the invitation

- ✓ Determine who is leading the meeting, including the logistics of scheduling the conference

    - Invite an Elder to start the conference with an opening prayer and land acknowledgment

- ✓ Draft an agenda for the conference with options for feedback and collaboration from the community members

    - If any data collection is going to take place at the conference, ensure that permission is obtained (ex. consent forms, permission to record, etc.)

- ✓ Develop questions that the host will ask the community members and consider sending these in advance

    - Consider the following questions:

        - What do you hope for the development of FASD resources?
        - What needs have to be met for this resource to be helpful?
        - What do you need to support this work fully?
        - What are anticipated barriers or challenges that could come up?

    - How can we support you if these challenges come up?

✓ Consider who is best positioned to facilitate the conference (ex. hire an external facilitator or connect with an internal staff member who could facilitate)

✓ Ensure that someone is assigned as note taker for each conference

✓ Send all relevant materials to community members, including any promotional materials

- Snacks, childcare, accommodations, or honorariums should be reflected in the promotional materials

✓ Conduct a debrief meeting with the internal team to review high level findings identified from the conference notes

- Brainstorm the ideas that arose from the conference and draft options for resource development based on community feedback

✓ Identify what follow up with community members will look like and determine how community members will be involved and communicated with moving forward

3. How to Approach this Work

Ways to Engage in the Work

When beginning to engage in resource development and awareness raising, it is important for the work to be guided by the following principles:

- **Trauma informed approach:** acknowledgement of past and current traumas, while creating safe environments and avoiding re-traumatization.

- **Evidence-based and results-driven approach:** findings that are grounded in meaningful data and indicators.

- **Cultural sensitivity:** acknowledgement of cultural contexts and values in relation to health.

- **Multi-sectoral and multi-agency collaborative approach:** various sectors will be engaged throughout the duration of this project.

- **Health equity lens:** be mindful of sex, gender, age, education, language, culture, geography and income.

The outcome was a result of the environment of safety that they created.

Keeping Momentum

If there are many staff and community members engaging in this work, creating a committee for the development of resources could be helpful.

This committee can support if determining the roles and responsibilities. While you can pre-determine roles and responsibilities, it is important to be flexible and mindful of the changing needs of the project. This committee can also keep track of tasks and deadlines and communicate with project funders, partners, and community if deliverables need more time to be completed.

It is important for this committee to not only include those with lived experience, but also centre their perspectives to ensure relevance and safety of resource developed.

Be Nimble and Adjust Approaches as Needed

Make adjustments to how you engage your clients and community for input in the design of the project or resource. Consider phone calls over in person visits, particularly during times of stress, whether that be personal stress, global health concerns or environmental stressors.

Meet individuals, organizations, and communities where they are at.

Have people that are passionate about it. That are wanting the most positive outcome as well.

4. Project Design and Delivery

This section looks at some questions to support in guiding your work and support in giving direction to the work moving forward. The following questions can help with providing direction for resource development:

- **What kind of resources will meet the need?**
  Often the first step of designing a project, as mentioned above, is to connect with the community to listen and understand the need and share back how their input will be reflected in the design of the project.

- **What is the goal for creating the resource?**
  An important piece of the design is knowing what the goals and desired outcomes of the project are. If this is kept top of mind throughout the process, including something to reflect back on through the duration of the project, then you can ensure to be making decisions that are going to ultimately get you to your goal.

- **Who do you want to engage with the resource?**
  Identifying who you hope to engage with the resource in the initial stages can help to determine how to move the project forward. This can also support in bringing community together to create buy-in for the project.

Project Management

When it comes to project management, engaging your team is an important step (as mentioned above), however there are some logistical considerations that can support with ensuring the direction of the project is on track as you will have a plan in place to refer back to. Important elements to have built out include:

- Outline of deliverables
  - Deadline, tasks, outcome, person responsible
- Objectives and Outcomes
- Budget

An important aspect of project management is ensuring that there is sufficient time and space to complete each step of the project and be able to communicate this with project funders in cases when tasks need more time and deliberation. Because the time between group discussions and decision making can be lengthy and things can change, it is important to communicate any changes made during this time.

Another aspect of managing a project is to ensure everyone involved in the project working team understand the context and sensitivities of the project in order to be active participants in the project.

5. Evaluation

An important step in the development and implementation process is to reflect on the lessons learned, both internally and externally. Creating space to connect back with the organizations and individuals that supported the work is an important step in learning what went well and what could be improved.

Evaluation is helpful for identifying ways to move forward in the work, and to advocate for further funding.

The evaluation should include opportunities for everyone's voices to be heard and should include community members, partners, and staff. Engaging in the evaluation could include:

- Surveys
- Interviews
- Sharing opportunities through stories, dialogue, or informal feedback
- Post activity reflections and debriefing

Furthermore, celebrating the successes of the project is a great way to bring together all participants.

The following provide a summary of key strengths, lessons learned, and recommendations.

Evaluation should include opportunities for everyone's voices to be heard.

6. Lessons Learned from the UFFOF FASD Project

✓ **Relationship Building**

- Continuity of staffing to support relationship building throughout the project

- Allowing for sufficient time for individuals to provide input or feedback

- Ensuring that community engagement happens at all steps of the project, to prevent experiences of tokenism and support community ownership

- Prioritizing voice of community members and lived experience

- Making decisions collaboratively

- Ensuring that changes to collaborative decisions are communicated clearly

✓ **Approach**

- Being trauma-informed, non-judgmental, and addressing stigma and stereotypes, and building a team which shares these understandings and values to prevent harm

- In terms of logistics, schedule meetings with ample notice and provide debriefing sessions

- Using considerate language which is guided by those with lived experience

- Ensuring adequate time and staffing

- Prioritizing the involvement and engagement of people with lived experience at every stage of the project

Ground the work in their wisdom.

Y is for

You

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Appendices

Social Determinants of FASD:
A Guide for Evidence-Based Implementation of FASD Prevention Approaches

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term that describes the experiences of individuals who were exposed to alcohol during prenatal development. All people[1] who consume alcohol and are able to get pregnant have the potential to expose a fetus to alcohol. Despite evidence of alcohol exposure and FASD in the scientific community, alcohol use during pregnancy is increasing, which demonstrates a need for improvements in knowledge exchange and prevention approaches (Denny et. al., 2020). The factors which influence alcohol exposure during prenatal development are related to a lack of knowledge that a person is pregnant, a lack of knowledge of the impact of alcohol exposure on fetal development and the relationship between trauma and alcohol consumption (RCY, 2021; Currie et. al., 2020; May et. al., 2020). These finding serve as the foundation for developing relevant prevention strategies which consider the underlying causes of prenatal alcohol exposure and broad spectrum of individuals at risk. Furthermore, the sections below provide a rationale for the inclusion of trauma-informed, harm-reduction, culturally safe and person-centered approaches in FASD prevention efforts.

Social Determinants of Health

There is little evidence to support the theory that FASD is more likely to occur within communities with reduced access to social determinants of heath (SDoH) (May et. al., 2020; Popoya et. al., 2020, RCY, 2021; Nathoo et. al, 2016). While some studies have suggested that FASD is more prevalent among communities with lower-socio-economic status and among Indigenous communities whom are more likely to experience barriers to accessing SDoH (Flannigan et. al., 2018), others have noted that these findings are influenced by racism and stereotypes rather than scientific evidence (RCY, 2021). For example, it was noted that white children from families with high education and socio-economic status were more likely to be diagnosed with Attention Deficit Hyperactive Disorder (ADHD) or Autism Spectrum Disorder (ASD) than Indigenous children who were more likely to be assessed for FASD, even when symptoms looked similar across communities. In addition to over representation in FASD assessment referrals, Indigenous communities are often targeted as research subject for FASD literature based on the assumption of a higher prevalence of FASD in Indigenous communities (RCY, 2021). Thus, focusing efforts on communities assumed to be higher risk may not be an effective strategy in reducing incidence of FASD and in fact perpetuate misinformation that prevent impactful dialogue in both non-marginalized and marginalized communities. It is important to consider that not all communities have equitable access to education, health care and financial resources when considering engagement strategies.

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1   The word people is used intentionally to acknowledge the existence and include the perspectives of trans men and non-binary people who have potential to become pregnant but do not identify with the female gender. For more context, please see the National Centre for Transgender Equality for educational resources https://transequality.org/issues/resources/transgender-sexual-and-reproductive-health-unmet-needs-and-barriers-to-care

Trauma-informed Practice (TIP)

One significant commonality among people who consume alcohol during pregnancy is a history of trauma and difficulty accessing support or coping with experiences of trauma (RCY, 2021; Currie et. al., 2020; May, et. al., 2020). Trauma-informed approaches can support access to FASD prevention resources for individuals coping with trauma. One key principle of trauma-informed practice which is relevant to FASD prevention is understanding the association between trauma and feelings of shame, fear and mistrust (KCHC, 2013). Families impacted by FASD have shared how shame, blame and stigma associated with FASD have been harmful and exacerbated challenges related to FASD (RCY, 2021). Skillful incorporation of TIP into prevention efforts can include a change in narrative from one that shames or blames individuals to a narrative which centers empathy, non-judgement and strength-based support (KCHC, 2013).

Harm Reduction and De-Stigmatizing FASD

Harm reduction is an approach that aims to reduce the negative impacts of substance use on child and maternal health while also addressing immediate safety and health needs rather than focusing on stopping use as the main strategy to mitigate harm. When supporting people who are struggling with substance use during pregnancy, an evidence-based harm reduction approach can include supporting lower barrier access to services and centering safety and relationship building when interacting with clients. It can also include supporting holistic needs such as basic needs, counselling, sexual health services, harm-reduction supplies or opioid replacements, advocacy and intersectoral collaboration (Nathoo et, al., 2015). Harm reduction approaches have been shown to increase engagement and retention in prenatal services and addictions services by reducing fear and improving trust between communities and care providers (Nathoo et, al., 2015).

Person-Centered Care

The person-centred approach, or women-centered approach when working with clients who identify as women, is designed to foster a collaborative relationship between childbearing clients and care providers whereby the expertise of both are respected and integrated into care (Fontein-Kuipers, et. al., 2018). Given that alcohol use during pregnancy is common and prevalent across social and economic groups a person-centered approach allows for the flexibility to meet the unique needs of diverse individuals while supporting them with FASD prevention. It also provides space for wholistic health needs of communities such as cultural perspectives and experiences of injustice or barriers to access to trauma services and social determinants of health to be noted and supported while working toward child and maternal health.

Cultural Safety and Humility

Cultural safety and humility is an approach which goes beyond the inclusion of cultural competence and cultural sensitivity to include and acknowledgement of how systemic and interpersonal racism influences care provided to Indigenous people (Baba et. al, 2013). A report by the Representative for Children and Youth (RCY) (2021), explained further that prevention efforts which target low-income and racialized communities such as Indigenous populations have the potential to perpetuate stigma and racism, without adequate evidence for an increased need for FASD prevention in marginalized communities. Thus, when approaching relationship building and engagement with Indigenous communities it is important to consider the ways in which FASD prevention strategies and educational resources can exacerbate experiences of racism, stigma and trauma for Indigenous communities.

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