

CHANGING THE CONVERSATION

**CNFASD PARTNERSHIP SYMPOSIUM
FEBRUARY 6 & 7, 2019
WINNIPEG, MANITOBA**

Report Summary

ACKNOWLEDGEMENTS

The Canada Northwest FASD Partnership pools resources in order that a member jurisdiction can host a conference every third year and symposia in the two years in-between. A special thank you for the opportunity to host this national symposium in Manitoba.

Manitoba would like to express great appreciation for the support from the following organizations who made the symposium an even greater success:

- ❖ The Canada FASD Research Network for supporting the attendance of their Family Advisory Committee and researchers.
- ❖ The University of Manitoba (SSHRC grant) for supporting the attendance of several northern and rural members of the provincial FASD coalitions
- ❖ Manitoba Liquor and Lotteries for their ongoing support in engaging with the FrameWorks Institute and for funding our facilitator from InVision Edge, Rhonda Honke.
- ❖ The regional Public Health Agency of Canada office for helping with venue costs.
- ❖ The Addictions Foundation of Manitoba for helping with venue and supply costs

Special thanks to our Keynote Speaker, Dr. Nathaniel Kendall-Taylor, CEO, FrameWorks Institute.

A big thank you to all of those that participated on the planning committee.

Last, a thank you to the Human Rights Museum of Canada as the venue for our symposium.

“It exceeded my expectations. I expected it to be networking and educational but it was engaging, fun, hard and different.” ~ Symposium participant

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Objective of Report:

This report provides documentation of the *Changing the Conversation* Symposium (2019) held by the CNFASD (Canada Northwest Fetal Alcohol Syndrome Disorder) Partnership on February 6 and 7, 2019 in Winnipeg, Manitoba. It includes an overview of the activities undertaken, an inventory of the prototypes developed, evaluative feedback by attendees and participants, and details of planned and suggested next steps for moving forward. The objective of this report is to provide participants with insights and lessons learned from the symposium that may guide future work at the local and national level. Moreover, this report will set the stage for continued work in reframing FASD, per the short-term, mid-term, and longer-term action plans articulated on pages 5 and 6.

Pre-Symposium Work:

Manitoba has FASD coalitions in communities across the province. These coalitions lead grassroots initiatives to promote FASD prevention and support in their communities. In 2013, these coalitions came together and determined that stigma towards women who drink during pregnancy and towards people with FASD is one of the biggest barriers to FASD initiatives in Manitoba. A unanimous decision was made to embark on a province-wide project that would address stigma in order to: decrease barriers to women accessing support services during pregnancy; help the public see the strengths, potential, and gifts of people with FASD; increase dignity-promoting media coverage about FASD; support effective, dignity-promoting service and resource development; and decrease isolation among parents and caregivers of people with FASD. This project was given the name *Looking After Each Other: A Dignity Promotion Project*¹. Communication about FASD has been a major focus of the Looking After Each Other project. It became clear that in order to reduce stigma, a fundamental shift is needed in the way Manitobans and Canadians think and talk about FASD. With the understanding that communication was needed as a central focus, three important initiatives began:

¹ More information on the Looking After Each Other Project can be found at: www.fasdcoalition.ca/looking-after-each-other-project

1. The [Language Guide](#) was developed to provide alternative words or phrases for those commonly used by society when discussing FASD.
2. Three [videos](#) were developed to share messages that promote dignity and showcase how communities can make a difference.
3. With the help of its funding partners (CanFASD Research Network, Manitoba Liquor and Lotteries and Addictions Foundation of Manitoba), the project engaged with the FrameWorks Institute to develop a report, [Seeing the Spectrum: Mapping the Gaps between Expert and Public Understanding of FASD \(2017\)](#).

The *Seeing the Spectrum* report revealed the gaps between public and expert understanding of FASD. Stemming from a “mapping the gaps” analysis, the report offered some initial recommendations on how to redress these gaps. This report served as a foundational document to the *Changing the Conversation* Symposium (herein, referred to as the symposium), underpinning its activities and work focus. The *Seeing the Spectrum* report offers insights on how to frame/reframe FASD. A summary of the report is found in Appendix E.

Symposium Goals:

The main goals of the symposium were:

- a) To bring together and engage a diverse group of national stakeholders to discuss and rethink the ways we talk about FASD, including the importance of promoting dignity with respect to FASD and alcohol use in pregnancy.
- b) To help symposium participants gain a greater understanding of the reframing process.
- c) To provide symposium participants with opportunities to contribute to the reframing of FASD in a meaningful way.
- d) To inspire symposium participants to take back an idea for reframing to their home communities and organizations for further reflection.
- e) To create initial ideas for reframing FASD that could be reviewed, assessed, and enhanced, through the application of reframing research and the lessons learned from the *Seeing the Spectrum* report.

The symposium brought together a group of over ninety stakeholders from all provinces and territories across Canada to create ideas on how to rethink the way we talk about FASD in Canada. Ensuring diversity of the symposium participants was of significant importance to the planning committee. Concerted efforts were made to bring together a representative mix of professionals from a variety of sectors (e.g., health, social services, education, justice, and industry), parents and caregivers, and people with FASD. Table 1 provides details on the background of those participants who completed the symposium evaluation survey, a sample of 53 participants. Of these 53 participants, 29 self-reported a high level of knowledge of FASD; 21 self-reported a medium level of knowledge of FASD; one self-reported a low level of knowledge of FASD; and two participants responded “unsure”. Overall, the majority of participants reported medium to high knowledge of FASD, not an unexpected finding.

Table 1: Background of Symposium Participants

Type of Background, self-reported (more than one background description could be declared)	Number of Participants (n=53)
Service provider	22
Caregiver/parent	13
Policy maker	9
Educator	6
Researcher	6
Communications/media	4
Alcohol industry rep	2
Healthcare provider	2
Person with FASD	2
Elder	1

Table 2: Geographical Background of Symposium Participants

Geographical Background	Number of Participants (n=94)
Manitoba	42
Alberta	10
British Columbia	8
Ontario	7
Saskatchewan	6
Northwest Territories	5
Quebec	4
Nunavut	3
Yukon	3
New Brunswick	2
Newfoundland and Labrador	2
Nova Scotia	1
Prince Edward Island	1

Outcomes of Success:

Per the development work of the planning committee, the two main outcomes of the symposium were identified as: a) gained understanding by participants on the importance of framing FASD and; b) gained knowledge of reframing FASD and alcohol use during pregnancy. These outcomes were achieved, as demonstrated through statistical testing detailed on pages 28 and 29. Two indicators were developed to assess these outcomes, including a paper survey disseminated to each symposium participant and an interview guide to lead six individual interviews with selected key informants. In addition to the survey and individual interviews, a focus group with key stakeholders and symposium planning committee members was conducted post-symposium. The results from these data collection methods are incorporated throughout this report. A copy of the survey and the interview guide are found as Appendix D and E, respectively.

Moving Forward:

Short-term Action Plans: Following the symposium, there are a number of planned activities to maintain momentum and move the reframing conversation forward. Per the symposium participants' agreement, each individual will take back insights and lessons learned on reframing FASD to their home communities and organizations. Three months after the symposium (May 2019), the symposium planning committee will administer a follow-up evaluation survey to determine how individual participants have made progress in framing within their home communities and organizations. Further, the symposium materials are available via the following on-line links, provided by Healthy Child Manitoba Office:

- [Final Report on the 2019 CNFASD Partnership Symposium](#)
- [Keynote Address by the FrameWorks Institute's CEO, Dr. Nat Kendall-Taylor](#)

Mid-term Action Plans: Within the next six months, working groups within interested jurisdictions will be established to continue knowledge translation work of the *Seeing the Spectrum* report and other framing/reframing best practices.

Longer-term Action Plans: It is hoped that ongoing work on framing/reframing FASD will continue across Canada, as per the lessons learned from the *Seeing the Spectrum* report and the symposium. This will include jurisdictions and communities working together to learn more about what reframing entails in their context, and supporting rigorous testing and evaluation of reframing ideas to ensure their fidelity to the *Seeing the Spectrum* report. Sharing and discussion will continue to move this agenda forward, with the hope of creating greater public understanding of FASD and increased support for services that promote dignity and inclusion for people with FASD and women who use alcohol in pregnancy.

About the CNFASD Partnership:

The CNFASD Partnership was initially formed in 1998 between the Ministers of Health and Social Services from Manitoba, Saskatchewan and Alberta in their recognition of the impact of FASD on society and that positive results could be achieved that would benefit those affected, families, communities and government. By 2001, the CNFASDP membership grew to include British Columbia and all three territories. The goal of the CNFASD Partnership is to advance evidence-

based policy development and service design in FASD prevention, diagnosis and support through the sharing of resources and expertise.

Every three years, the CNFASD Partnership hosts an FASD conference for families, service providers, researchers, educators and government officials with a focus on advancing one or some areas of its Strategic Priorities Plan. A symposium on FASD is hosted in at least one of the off years in which a CNFASD Partnership conference is not held. The purpose of the symposia is to provide a smaller forum where professionals from across Partnership jurisdictions can come together to discuss issues specific to their area of practice and/or research and that focus on an area or areas of the Strategic Priorities Plan.

The host jurisdiction for the conference and symposia is chosen by consensus of the Partnership at least one year in advance. Depending on the scope of the event, the host jurisdiction may solicit participation of a Steering Committee member from another jurisdiction in planning the event. The Steering Committee supports the host jurisdiction to designate conference /symposia themes from within the Partnership Strategic Priorities Plan that address emerging issues that warrant focused attention. Per consensus of the Steering Committee, the symposium for 2019—Changing the Conversation—was hosted by Manitoba and the theme selected was framing FASD to promote dignity.

About FrameWorks Institute:

Founded in 1999, FrameWorks Institute (FWI) is a non-profit think tank, based in Washington D.C, which advances the mission-driven sector's capacity to frame the public discourse about social and scientific issues. The organization's signature approach, Strategic Frame Analysis®, offers empirical guidance on what to say, how to say it, and what to leave unsaid. FrameWorks Institute designs, conducts, and publishes multi-method, multi-disciplinary framing research to prepare experts and advocates to expand their constituencies, to build public will, and to further public understanding. Over the past two decades, FrameWorks Institute's social science research has grown to a database of more than 400,000 participants and 400 research studies. The organization has investigated the communications aspects of over 40 social and environmental issues. To make sure its research drives social change, FrameWorks Institute supports partners in

reframing, working alongside leading funders, advocates, and scientists who are engaging the public on our most critical social issues.

About Framing:

As defined by Nat Kendall-Taylor, CEO of the FrameWorks Institute, in the symposium's keynote address, framing is the study of "how changing the way we present information changes the way that people perceive issues and act as a result." Dr. Kendall-Taylor outlines three key reasons why framing is so important to social issues such as FASD:

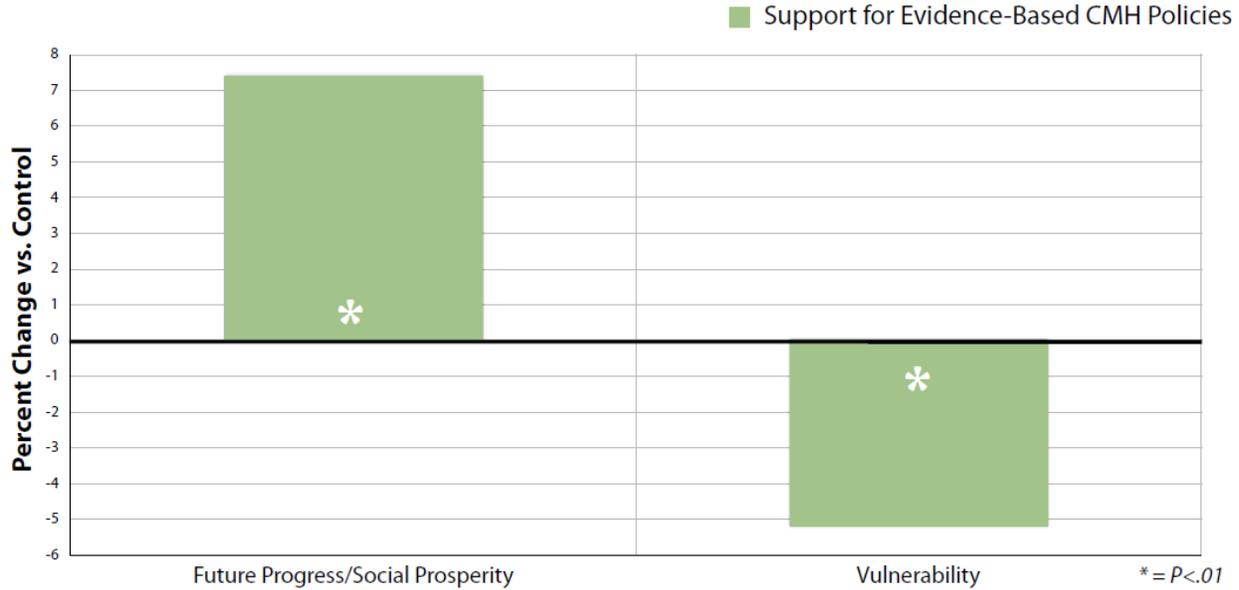
1. **Understanding is frame dependent.** (It's not just *what* you say, it's *how* you say it.)

Ensuring the content of a message is accurate matters a lot, but the way the content is presented is equally important. Choices about the language and values we use to communicate about an issue determine whether or not our communication has the effect we intended.

2. **We have a problem of communication and perception.**

We may say one thing to the public ("AAA"), but the information doesn't land in the way we thought it would, and the public hears something different ("BBB") and the information does not gain traction, or worse, it sends the public in a direction we do not want them to go. For example, as shown in Figure 1, different frames for children's mental health can yield markedly different results. When the frame of future progress and social prosperity is used to describe children's mental health, public support for evidence-based programs increases. Conversely, when the vulnerability frame is used, public support decreases. Information is always interpreted through the values and beliefs held by individuals and communities. This emphasizes the importance of knowing patterns of public values and beliefs, and using caution and rigorous testing of messages and information, in order to become more effective and strategic communicators.

Figure 1: The Differing Impacts of Two Distinct Frames (Source: FWI)



3. Sustained social change requires changes to the ways we communicate

If we can change the way that an issue is communicated to the public (change the ‘environment’ of information people are receiving), over a long period of time, space can be created: space for the public to change the dialogue, space for people to think, behave and act differently.

Learning how to successfully frame FASD is neither easy nor intuitive. It requires a focused, thoughtful and robust process of scientific testing. The first step is to understand how the public views an issue. This first step was addressed by FrameWorks Institute and the results are captured in the *Seeing the Spectrum* report.

Key Findings from the Seeing the Spectrum Report:

As sourced from the *Seeing the Spectrum* report (2017), there are several differences in the understanding of FASD between experts and the general public. Such differences impact on FASD messaging which can, inadvertently, reinforce negative stereotypes and decrease public support in FASD. Through a mix of qualitative and quantitative methods, The Frameworks Institute conducted strategic communications research to reveal the cultural models that underpin

the ways in which the general public thinks about FASD. The following provides two examples of these cultural models, taken from the *Seeing the Spectrum* report (2017):

Individualism: This type of thinking leads people to see a woman’s choices—typically regarding a healthy diet, frequent exercise, and sufficient rest—as the sole determinants of a successful pregnancy. Individualism thinking, and the primacy of personal choice and willpower in determining wellbeing, shapes the public’s belief that any choice deemed unhealthy is the result of a lack of willpower or poor decision-making, and only the individual in question is at fault.

Fatalism: The public believes that if you have FASD, your brain is damaged permanently and nothing can be done. The public shares an understanding that the cognitive differences caused by prenatal alcohol exposure are deep, foundational and set in stone; making it exceedingly difficult for the public to believe that viable and effective solutions exist. They see individuals with FASD as fundamentally different and in a class apart from those the public considers ‘normal’. It casts those with FASD as deeply and permanently “other”.

Key Recommendations for Reframing FASD:

The *Seeing the Spectrum* report tells us that FASD is a top-of-mind issue for many Canadians. That is to say, because people care about FASD, we have opportunities to engage with the public to reframe. Some of the ways that Canadians currently make sense of FASD, such as understanding that alcohol use during pregnancy may be related to coping with trauma and/or addiction, provide opportunities to increase public understanding and promote dignity.

Other beliefs, such as believing that once you have FASD your brain is damaged and nothing can be done, tend to lead people to develop stigmatizing views and ineffective solutions. Increasing the public’s understanding that the brain can change in response to our experiences throughout life (plasticity) emphasizes that effective solutions are entirely possible, and that when we work together in practical ways to support people with FASD we can make a positive difference.

The four key recommendations provided by FrameWorks to help Canada move forward to change conversations about FASD are:

1. *Get Context In*

Currently, society tends to use frames of understanding about FASD that focus on individuals, rather than a focus on contextual and societal frames. These frames lead people to see issues as a result of individual people's decisions. This results in expecting individual solutions: i.e. "people should make better decisions and try harder." We need to frame our messages so that understanding of contextual factors and social solutions are cued. For example, we need to cue how the social determinants of health impact alcohol use, and how better services and more support for people who drink alcohol during pregnancy are effective social solutions. Three ways to re-balance individual and social frames are:

- Emphasize the role of social context- "what surrounds us, shapes us"
- Communicate that change is possible (dynamism)
- Emphasize interdependence- avoid looking as an issue in isolation, and emphasize that what affects one of us, affects all of us.

2. *Hook and Pull*

By determining the frames and understandings that currently exist in our culture, we can work to actively cue frames that open the public to a deeper understanding about FASD. FrameWorks recommends cueing the following frames:

- Talk about the importance of context and past experiences (in regards to people who drink during pregnancy and people with FASD)
- Talk about the ways in which addiction may impact a person's individual choice
- Talk about the importance of fetal and early childhood development, but balanced equally with emphasis on how there is always potential for change.

3. *Urgency and Efficacy*

Often, we communicate the urgency of a social issue, which helps increase the public's motivation to address the issue. However, if a strong sense of efficacy, which is the understanding that we know what to do to address the issue, is not emphasized equally, people may feel defeated and may resort to thinking "there's no way we can solve it, I'm going to disengage." Therefore we need to find a balance between urgency and efficacy. It is recommended that when talking about FASD, we:

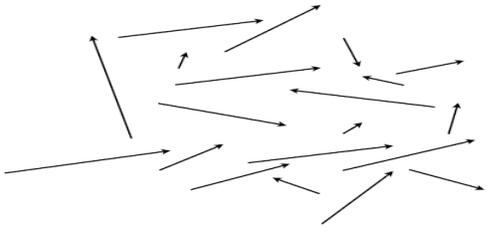
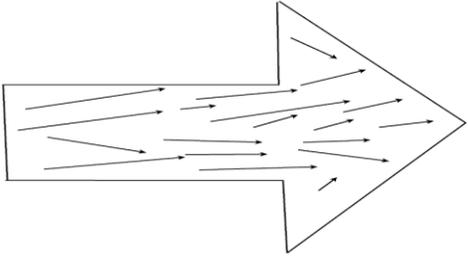
- Cue the value of ingenuity- communicate that there are innovative solutions that are possible, and that people are already working on
- Give specific concrete examples of solutions, and adopt a tone that conveys efficacy
- Strike a “50/50” balance: spend 50% of your time talking about the problem, and 50% of your time talking about solutions.

4. *Tell a Story*

Humans fundamentally think, remember, process, and re-tell information in story. This is the single most powerful thing we can do to get information across. Tell “wide angle” stories that balance the individual and their context, in order to avoid reinforcing stigma and over-emphasis on an individual choice. Tell stories that talk about culture and relationships, why the issue matters, how it works, what makes it complicated, and what solutions there are.

Building on the key findings of the *Seeing the Spectrum* report, the goals of the symposium were to begin a conversation about the importance of framing and to understand why we need to come together to reframe FASD through a consistent, unified approach. As learned from the *Seeing the Spectrum* report, if we change the way an issue is framed over a long period of time using public discussion we can change public discourse about that issue. “When we change public discourse we create space—space for people to think, behave and act differently” (Dr. Nat Kendall-Taylor, CEO, Frameworks Institute). Figure 2, sourced from Dr. Kendall-Taylor’s keynote presentation delivered at the symposium, illustrates the power of a consistent, unified approach to framing.

Figure 2: Arrow Depiction of Framing (Source: FWI)

	
<p>Public discourse about an issue often starts like this: we all tell different stories, which creates confusion and deepens people’s current ways of thinking.</p>	<p>What we want are all the arrows going in the same direction, a set of common frames, a common narrative, a set of ideas we all advance which move us in the same direction.</p>

About Innovation Engineering:

InVision Edge is a Manitoba organization that specializes in using Innovation Engineering. Innovation Engineering is a new field of academic study and leadership science developed by the Eureka Ranch, thought leading companies and universities. It teaches advanced methods and tools for creating big ideas, accelerating projects, and problem solving daily challenges. Innovation Engineering applies system thinking to strategy, innovation and how to work together within companies, non-profits, universities and communities. Innovation Engineering uses many different methods to create ideas, communicate ideas clearly and persuasively, commercialize ideas, and implement systems-driven leadership.

Recognizing one of the main goals of the symposium was to bring together and engage a diverse group of national stakeholders to discuss and rethink the ways we talk about FASD, the symposium planning committee chose InVision Edge to facilitate day one of the symposium. Using Innovation Engineering approaches, InVison Edge encouraged participants to think “outside the box” and leverage the diversity in the room to generate new, innovative ideas on how to communicate more effectively about FASD.

Overview of Symposium Agenda:

The symposium agenda is found as Appendix A. The following synopsis describes the key activities for the two-day symposium, and the main objectives for each.

Day One:

- 1) Opening Prayer and Address, Elder Dave Courchene.
- 2) Welcome and introductions by CNFASD Partnership symposium host, Sarah Guillemard, Member of the Manitoba Legislative Assembly; and Holly Gammon, Healthy Child Manitoba Office.
- 3) Keynote: Dr. Nathaniel Kendall-Taylor, Chief Executive Officer, FrameWorks Institute.
- 4) Innovation engineering: Idea generation activities led by facilitator Rhonda Honke

Day Two:

- 1) Innovation engineering: Ideas for pitch development led by facilitator Kathy Andrew.
- 2) Idea pitches: Presentations delivered by each thematic group.

Day 1 Symposium Activities:

The goal and focus of day one was idea generation. A number of Innovation Engineering tools and methods were used, led by Rhonda Honke and supported by five (Manitoba-based) facilitators. These activities were guided by “blue cards”, as shown in Appendix B and C. The two questions stated in the blue cards were:

- How can we talk about alcohol use during pregnancy without judgment?
- How do we have conversations with and about people with FASD that are more strength-based and better connected to larger disability conversations in Canada?

Ideas were generated through small group discussions and were captured on “yellow cards”, as shown in Figure 3, completed by each symposium participant. Participants were encouraged to generate as many ideas and complete as many yellow cards as possible. Some of the activities that encouraged idea generation were:

- ❖ Mind Dump
- ❖ Headline
- ❖ Spark Deck
- ❖ Mind Mapping
- ❖ Do One Thing Great (Roll the Dice)
- ❖ Osborn's Checklist
- ❖ The Gauntlet

Alongside these small group activities were periodic large group reflections and idea sharing.

Figure 3: Sample Yellow Cards

Final

INNOVATION ENGINEERING **INVISION EDGE**

IDEA Card™
A framework for clearly communicating innovative ideas.
Fill in all that you can.

Name of Your Idea: We are One Community fabric
NAME that helps us understand the benefit of your idea.

NEWS HEADLINE: In a sentence – what makes your innovative idea MEANINGFULLY UNIQUE (new and different from anything that already exists)
We create strong community through individual journey's.

YOUR IDEA: What is the innovative idea, HOW does it work & WHAT is being done differently?
Create a fabric from material that tells the story of individuals then connect the fabric together to create a community mosaic

STAKEHOLDER: WHO, is the stakeholder(s) who benefits most from this innovation?
Individuals impacted with FASD and their families

PROBLEM: WHAT problem, challenge or barrier, specifically, does this innovative idea address?
Knowledge that all individuals create community and the more we support and know will help strengthen all parts of community

INNOVATION ENGINEERING **INVISION EDGE**

IDEA Card™
A framework for clearly communicating innovative ideas.
Fill in all that you can.

Name of Your Idea: Replace posters with mirrors
NAME that helps us understand the benefit of your idea.

NEWS HEADLINE: In a sentence – what makes your innovative idea MEANINGFULLY UNIQUE (new and different from anything that already exists)
It removes visual biases, stereotypes and "otherness" because you are staring at yourself in the ad/poster.

YOUR IDEA: What is the innovative idea, HOW does it work & WHAT is being done differently?
How do we reach the general public and make it identifiable and hit home for every, to reduce "otherness" → create mirrored-posters where it reflects your own face back @ you on back →

STAKEHOLDER: WHO, is the stakeholder(s) who benefits most from this innovation?
community, women, public

PROBLEM: WHAT problem, challenge or barrier, specifically, does this innovative idea address?

The Other Side of the Coin:

At the onset of the symposium, a collective art project was introduced. Participants were asked to write how they currently promote dignity on one side of a coin and then after, at the end of the symposium, were asked to write new ideas for promoting dignity on the other side of the coin. The two photographs below depict this artwork.

Figure 4: Coin Project

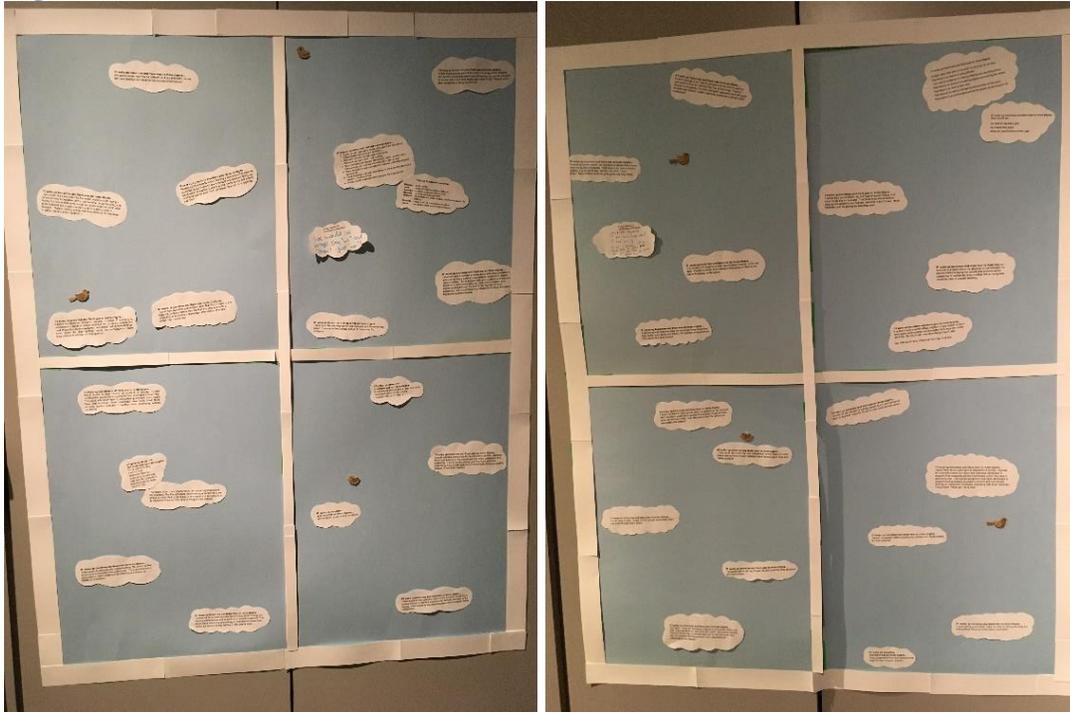


“If I woke up tomorrow and there was no more stigma...”

Family members, individuals with FASD and Elders who attended the symposium were asked ahead of time to send in their thoughts on the question, “What would your world look like if you woke up tomorrow and there was no more stigma about FASD?” During the 2 days some of their thoughts were read out loud to keep everyone focused on the goal of generating new ideas on promoting dignity and understanding for those impacted by FASD. These responses were also printed on to paper clouds and placed on a blue sky poster background, where attendees had the opportunity to add their own contributions throughout the symposium. After the symposium

Dorothy Reid took the readings and created this video: https://youtu.be/gUhhCE_CrGU

Figure 5: Windows and Clouds



A few sample responses include:

If I woke up tomorrow and there was no more stigma...

- *“I would feel freedom, inclusion, equality, a sense of belonging, a willingness to speak up and/or seek out help /supports (without the cost of sacrifice as once required). We would build one another up, there would be less fighting, more accommodations, more diagnoses and families coming together.”*
- *“No need to hide that I can't
So it looks like I won't
When all I want to know is how I can”*
- *“My life would go from black, grey and white to a bright spectrum of colours on a beautiful sunny day :)”*
- *“I would hear about the possibilities rather than the limitations, the hope for the future rather than the fear, the unique parenting strengths rather than the challenges, the promise of support rather than the silence.”*
- *“The impact of no more stigma would be beyond significant and life changing. The thought alone leaves me so amazed yet so sad and all at once. Sad to the reality of what we live in but amazed at all the possibilities we truly have to bring forward change.”*

The following photographs illustrate the idea generation process of day one.

Figure 6: Day 1 Idea Generation

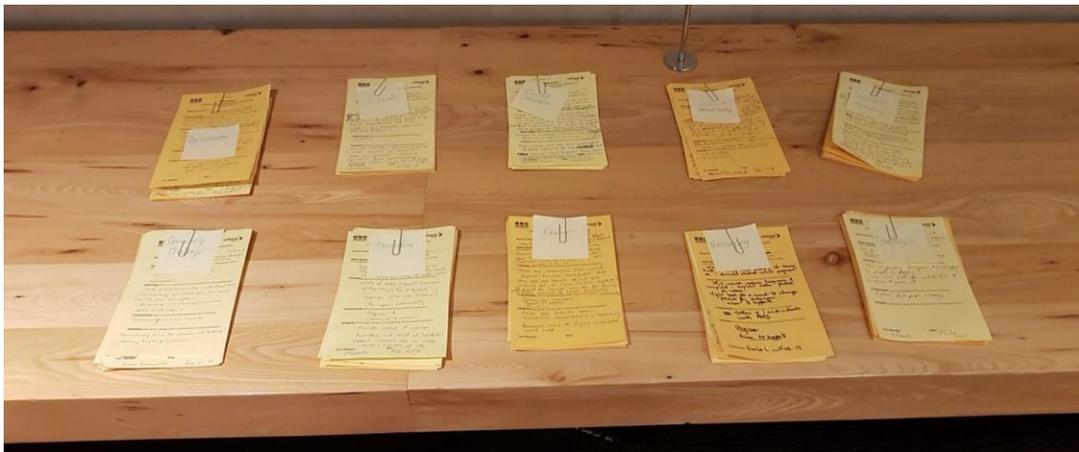


Day 2 Symposium Activities:

At the conclusion of day one, the Innovation Engineering facilitators organized the many yellow cards by the following ten themes:

- 1) Consulting with People with FASD
- 2) Visuals
- 3) Social Media
- 4) National FASD Communications Strategy
- 5) Community Mentoring
- 6) Awareness Campaigns
- 7) Messaging
- 8) Education
- 9) Storytelling
- 10) Community Challenge

Figure 7: Sorted Yellow Cards

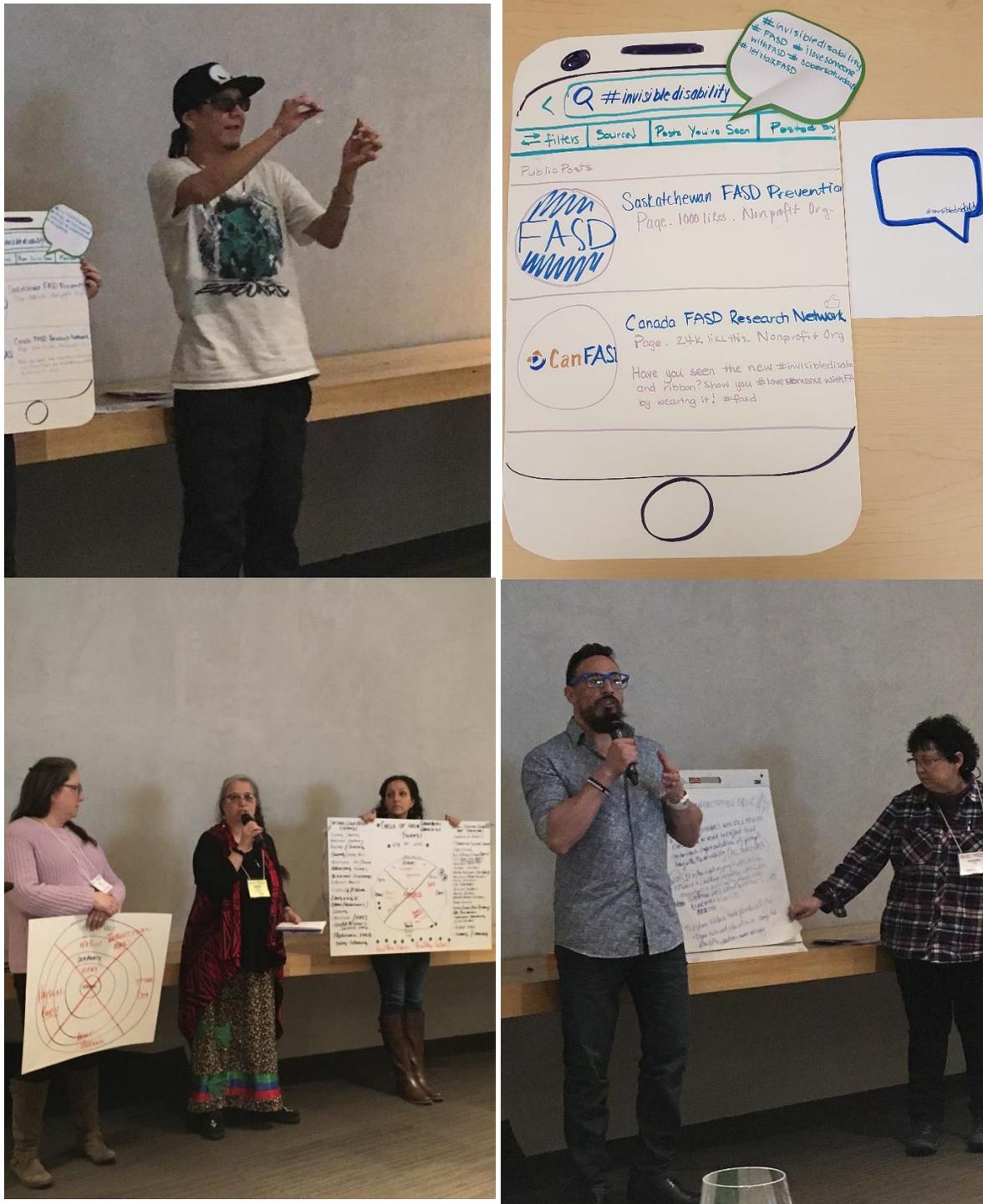


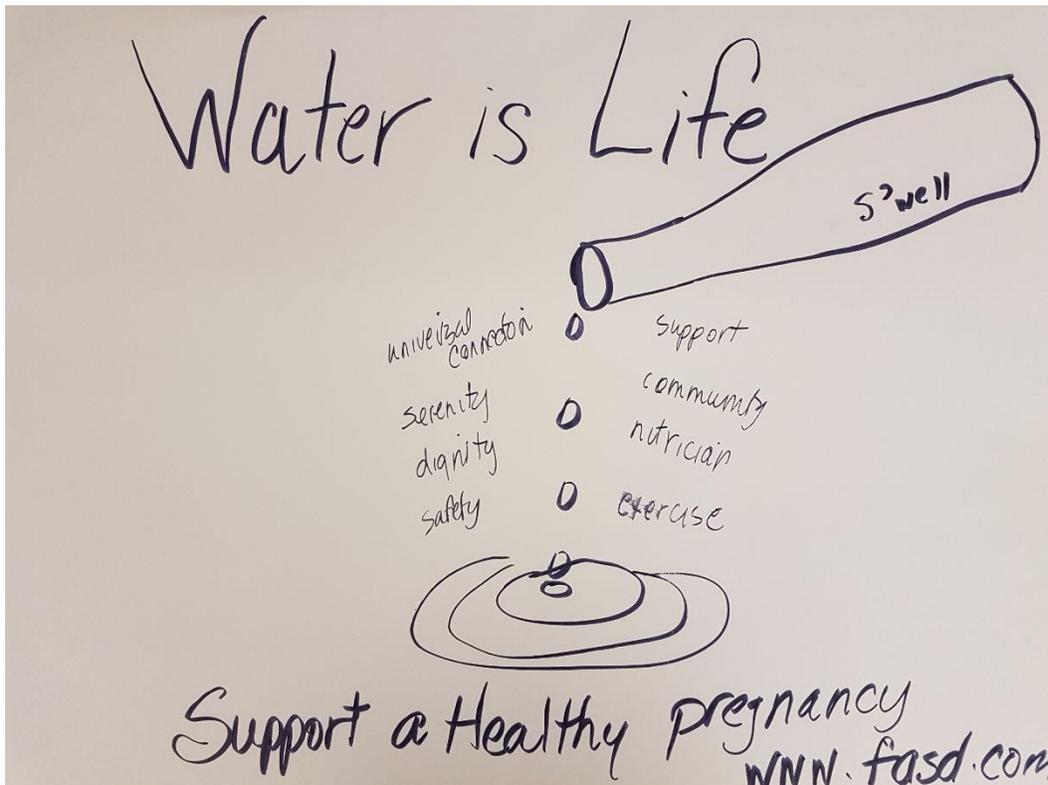
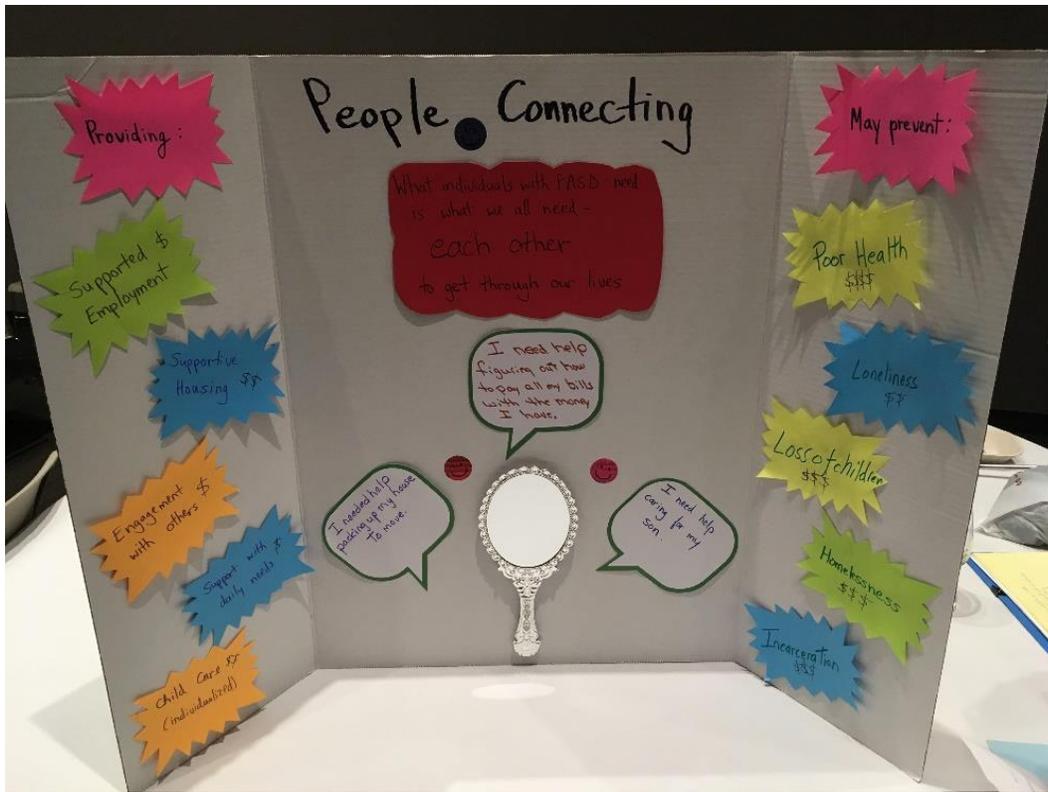
These themes were then used to launch the activities of day two, whereby participants worked to further develop ideas within the theme of their choice. On day two, each of the ten themes was stationed at a small table or two, and participants were invited to select a theme of their choice to work on throughout the day. Each small group reviewed the yellow cards within their theme and chose the top ideas to explore further. Each small group spent the morning of day two, thinking further and deeper about these ideas and developed a “prototype” or pitch to explain their idea. In the afternoon of day two, each small group pitched their idea to other small groups, in order to receive peer feedback and further refine their pitch. This activity culminated in final pitches by each small group to the large group. These final pitches were video-recorded and summary

descriptions for each are found in Appendix F.

The following photographs depict day two activities.

Figure 8: Day 2 Idea Pitches





Evaluation Details of the Symposium:

Feedback from the symposium participants was gathered through a paper survey (n=53) and interviews with six key informants (n=6). Additionally, a focus group was conducted with key stakeholders and symposium planning committee members. The following section presents the evaluative feedback from the symposium participants who participated in these data collection methods.

A. Did the symposium ensure participants psychological and cultural safety?

Importantly, a significant proportion of the symposium participants indicated that they were made to feel comfortable and safe to participate in the activities of the symposium. Details from the survey are found in Table 3. Using a Chi-Square Goodness of Fit test, it was found that more participants responded favourably to this question than statistically expected ($\chi^2=40.50$, $p < 0.05$), a finding that was statistically significant. That is to say, more participants responded “strongly agree” or “agree” to the question on safety (detailed in Table 3) than would typically be found.

Table 3: Made to feel Comfortable/Safe

n=53 (of the 53 survey respondents, none left this questions blank)	1 (Strongly Disagree)	2	3	4	5 (Strongly Agree)
I was made to feel comfortable / safe to participate in the activities of the Symposium.		5	6	16	26

Qualitative data from the evaluation survey and the key informant interviews corroborate this assessment. Further, it was noted that the offering of smudging contributed to psychological safety. As one respondent reported, “*collaborating, meeting new people, new creative ways to design the ideas. This can be tiring; smudging can help lift that tiredness*”.

However, of note, some survey respondents and key informants reported that the Day 1 activities were not safe or inclusive of the sensory needs of people with FASD.

Participant quotes:

“The speed dating exercise was very sensory overwhelming. I had to remove myself because it was too much. And I noticed that others did so too. It was especially difficult for people with FASD. It was hard to keep up with everything; there was just too much noise, too much activity.”

“There was definitely some frustration on Day 1. Difficult to connect it to the FWI elements. Not enough connection to the FWI principles—that got lost. So people remained in the old message thinking.”

“Some [activities] were good, some too much, especially on Day 1. Too many steps involved, too complicated, more complicated than necessary. I sometimes felt lost in the instructions, which took away from our time. Others at my table were feeling that too. We spent a lot of time on reviewing the instructions.”

B. Did the symposium ensure the promotion of diversity?

Importantly, a significant proportion of the symposium participants indicated that they felt the symposium was attended by a diverse audience, representing many service backgrounds and inclusive of people with FASD. Details of the survey are found in Table 4. Using a Chi-Square Goodness of Fit test, it was found that more participants responded favourably to this question than statistically expected ($\chi^2=60.89$, $p < 0.05$), a finding that was statistically significant. That is to say, more participants responded “strongly agree” or “agree” to the question on diversity and inclusion (detailed in Table 4) than would typically be found.

Table 4: Diversity and Inclusion

n=52 (of the 53 survey respondents, one left this question blank)	1 (Strongly Disagree)	2	3	4	5 (Strongly Agree)
The attendees of the Symposium were diverse and represented many communities and peoples.		3	3	16	30

Qualitative data from the evaluation survey and the key informant interviews corroborate this assessment.

Participant quotes:

“Yes, I felt I had opportunities to stand up and speak to the whole group. I felt heard as a professional, not just a token person with FASD. I really felt my expertise and perspective was asked and valued.”

“People worked well together, everyone was respectful, all opinions were valued. [The symposium] was conducive to brainstorming, no one was negative about an idea, everyone was very encouraging and positive.”

“Yes, I felt respected. The tables I was at, everyone was respectful of each other.”

Importantly, it should be noted that efforts to ensure the inclusion and respect of different epistemologies should continue to be a paramount focus. In particular, Indigenous ways of knowing and doing, with respect to FASD, are critically important, as one respondent articulates:

“At my table it was difficult to get away from old school thinking. It can be hard to incorporate an Indigenous perspective for some people, not all. To be culturally-safe, it is important not to treat FASD as an Indigenous issue, but it is also important to recognize its implications for Indigenous communities. That’s why it is important to apply a decolonizing lens to the issue. To understand the many layers to stigma that impact Indigenous peoples. So we need to learn how to address those many layers.”

C. Did the symposium meet participants’ expectations?

39 participants responded that “yes” the symposium met their expectations; one participant responded “no”; and 13 participants responded “unsure”. For those participants who responded “unsure”, the majority indicated that they did not know what to expect from the symposium. This may be an indication that more pre-symposium information and background could have been shared to better prepare participants. Qualitative data from the evaluation survey and the key informant interviews corroborate this assessment.

Participant quotes:

“It exceeded my expectations. I expected it to be networking and educational but it was engaging, fun, hard and different.”

“I was unsure of what exactly we were going to be doing, but was pleasantly surprised”.

“Yes. It met my hopes.”

D. Was the symposium theme of framing/reframing well received by participants?

Overall, participants enjoyed the focus of the symposium that of “changing the conversation” related to FASD and the goal to eliminate stigma and promote dignity. Many of the participants reported having read the pre-symposium work assignments, including the *Seeing the Spectrum* report (2017), as developed by FrameWorks Institute. Moreover, the majority of participants reported very favourable reviews of the Keynote speaker, a representative of FrameWorks Institute and a lead author of the *Seeing the Spectrum* report. Table 5 details this analysis.

Table 5: Keynote Speaker

n=44 (of the 53 survey respondents, 9 left these questions blank)	1 (Strongly Disagree)	2	3	4	5 (Strongly Agree)
Keynote address by Dr. Kendall-Taylor, FrameWorks Institute			1	13	37

Qualitative data from the evaluation survey and the key informant interviews corroborate this assessment.

Participant quotes:

“I think that the language that you use frames the way people think about a situation so the goal of the symposium was to get people thinking differently about their work and how some of FrameWorks findings can and should be implemented. I think that that was really great.”

E. Were the innovation engineering activities effective in generating new ideas for framing?

As detailed in Table 6, in general the participants rated the innovation engineering activities of the symposium favourably. Reviews of the Day 2 activities were especially well received. In contrast, however, a large proportion of the symposium participants rated the activities of Day 1 unfavourably, stating that the pace felt rushed, that the instructions were confusing,

and that some of the activities (e.g. The Gauntlet) were overwhelming and unsafe, especially for the people with FASD, as cited earlier on pages 10 and 11. Survey details are found in Table 6.

Table 6: Innovation Engineering Activities of Symposium

n=44 (of the 53 survey respondents, 9 left these questions blank)	1 (Strongly Disagree)	2	3	4	5 (Strongly Agree)
Day 1 activities (mind mapping, spark deck, gauntlet)	9	10	11	16	4
Writing yellow cards	2	9	15	21	3
Day 2 activities (prototypes, pitching your idea)		2	9	24	17

Qualitative data from the evaluation survey and the key informant interviews corroborate this assessment.

Participant quotes:

“I have never attended a meeting where we have done this type of approach. So I have found it very interesting and it’s actually one of the reasons why I wanted to participate and see what that was like.”

“I enjoyed the activities on Day 2, the opportunity to present our message prototypes. Day 2 was more concrete and individuals with FASD would have a better time with that kind of approach.”

“On Day 1, our table wanted to stick with an idea but we had to move on, but that was good. And then the second day had opportunity to come back after letting it sit.”

“The process was fantastic – it got us thinking a lot of things. Inspirational. Amazing!”

“Day 2 it was really interesting to work toward a specific topic. I switched tables / themes. It was good to connect with the people at that table. Solidifying our idea into a prototype forced us to complete our thinking from day one and pick out core elements.”

“You couldn’t sit quietly at the back and slink away as you might be able to do at other conferences. This was busy and a lot of work. It was a great use of time, especially given that it brought folks from other provinces, so a good use of time. Very intense, rapid. I was a little petered out at the end of day 1.”

“One drawback was you’d get into a good conversation and then we were told to stop and move on to a new idea or topic. So it felt hard to switch focus, but that was part of the point, to generate lots of ideas.”

“The facilitators were good, but at times it felt that they were interrupting a little too much, but I get that they were trying to move the discussion forward and get more ideas from us.”

“Day 1 was very fast paced, but I know why it was like that. So I rolled with it. The pace was different for the person with FASD at my table. I would say it was not a best format to use for people with FASD, but it was a good way to generate a lot of ideas.”

F. Did the symposium inspire new ideas on how to address stigma related to FASD and alcohol use during pregnancy?

40 participants responded that “yes” the symposium inspired new ideas on how to address stigma related to FASD; three participants responded “no”; and 10 participants responded “unsure”. In contrast, 25 participants responded that “yes” the symposium inspired new ideas related to alcohol use during pregnancy; 17 participants responded “no”; and 11 participants responded “unsure”. From this analysis, it appears the symposium was more effective at generating ideas to address stigma related to FASD than to alcohol use during pregnancy. Qualitative data from the evaluation survey and the key informant interviews demonstrate the symposium’s success in generating solution-focused ideas related to FASD.

Participant quote:

“Usually the discussion is focused on the issue or the problem, but this one was focused on the solutions, which was nice.”

“It was work-based, forward thinking. The intention was to generate ideas and work as a team, so it felt more like a research project versus a professional development learning. And on a broader scale, a Canadian scale, it was very powerful to see the similarities across Canada and to start thinking on a national level. Not like anything else I’ve attended.”

G. Will the symposium facilitate future action in home communities and organizations?

A significant proportion of the symposium participants indicated that they will take back an idea for reframing to their home community or workplace and discuss it with others. Further, some of the symposium participants indicated that they will be able to implement one of their ideas in their home community or workplace. In comparison, more participants reported that they will be able to take back ideas for reframing to their home communities and workplaces, while fewer participants reported that they would be ready to implement a new idea for reframing with their home communities or workplaces. Details of the survey are found in Tables 7 and 8.

Table 7: Ideas for Reframing

n=53 (of the 53 survey respondents, none left this questions blank)	1 (Strongly Disagree)	2	3	4	5 (Strongly Agree)
I will take back an idea for reframing to my home community or workplace and discuss it with others.			10	24	19

Using a Chi-Square Goodness of Fit test, it was found that more participants responded favourably to this question (Table 7) than statistically expected ($\chi^2= 43.19$, $p < 0.05$), a finding that was statistically significant. That is to say, more participants responded “strongly agree” or “agree” to the question on taking back an idea for reframing than typically would be found.

Table 8: Implementation of Ideas for Reframing

n=52 (of the 53 survey respondents, one left this question blank)	1 (Strongly Disagree)	2	3	4	5 (Strongly Agree)
I will be able to implement one of these ideas in my home community or workplace.		3	19	18	12

Using a Chi-Square Goodness of Fit test, it was found that more participants responded favourably to this question (detailed in Table 8) than statistically expected ($\chi^2= 28.58$, $p < 0.05$), a finding that was statistically significant, however this favourable response is lower compared to the question detailed in Table 7.

Survey data detailed in Tables 7 and 8 are enhanced by the qualitative data from the evaluation survey and the key informant interviews that reveals the types of ideas and actions participants will bring back to their home communities and workplaces.

Participant quotes:

“I will reframe how I say things.”

“I will use [FrameWorks] chart in all my communication and education.”

“I will continue to communicate dignity.”

“I will be kinder, less judgmental, more open minded.”

“I will think about the language that I use.”

“I will discuss and brainstorm how to further the conversation in my home community.”

H. Did the symposium lead to gains in knowledge?

Survey results demonstrate a statistically significant gain in knowledge of framing/reframing social issues, as attributed to the symposium. Using a Wilcoxon signed-rank test (the non-parametric equivalent to a paired difference t-test), a statistically significant difference was found in the self-reported knowledge on how to frame/reframe social issues of participants (Z

= -5.43, $p < 0.05$). The median self-reported knowledge rating was “3” before the symposium and “4” after the symposium (this higher rating indicates greater self-reported knowledge). Details of the survey are found in Table 9.

Table 9: Pre/Post Gains in Knowledge on How to Reframe/Frame

n=51 (of the 53 survey respondents, two left this questions blank)	1 (Low)	2	3	4	5 (High)
Before the Symposium, my knowledge on how to frame/reframe social issues was....	8	10	18	11	4
After the Symposium, my knowledge on how to frame/reframe social issues is...			7	28	16

I. Did the symposium lead to gains in understanding?

Survey results demonstrate a statistically significant gain in understanding of the importance of reframing FASD and alcohol use during pregnancy, as attributed to the symposium. Using a Wilcoxon signed-rank test (the non-parametric equivalent to a paired difference t-test), a statistically significant difference was found in the self-reported understanding of the importance of reframing FASD and alcohol use during pregnancy of participants ($Z = -4.36$, $p < 0.05$). The median self-reported understanding rating was “4” before the symposium and “5” after the symposium (this higher rating indicates greater self-reported knowledge). Details of the survey are found in Table 10.

Table 10: Pre/Post Gains in Understanding of Importance of Reframing/Framing

n=52 (of the 53 survey respondents, one left this questions blank)	1 (Low)	2	3	4	5 (High)
Before the Symposium, my understanding of the importance of reframing FASD and alcohol use in pregnancy in order to promote dignity was...	3	5	16	15	13
After the Symposium, my understanding of the importance of reframing FASD and alcohol use in pregnancy in order to promote dignity is....		1	3	19	29

As articulated by one participant, “*there was a great “aha” moment when a person with FASD at my table spoke about his issue with strength-based framing. That made me rethink a lot about what I thought I knew about strength-based framing.*” This participant describes further a “huh” moment, when the table discussion focused on the different goals of prevention work and support work, stating that, “*there was some discussion about moving prevention into the public health sphere, and the supports work into services.*”

J. What broad scale actions are needed for furthering the symposium work?

Qualitative data from the evaluation survey and the key informant interviews provided important details related to broad scale and nationally-focused work in FASD. Many participants pointed to the need for a national-level framing strategy that would yield consistent messaging and a united focus and goal.

Participant quotes:

“We need to come together as a unified group”.

“We will need a coordinated and unified approach”.

“The more we work together and take a coordinated approach, the stronger we’ll be and the more we’ll be heard”.

“We must all be pointing in the same direction”.

“We need a national strategy and buy-in by the federal government”.

“We need to change the message and all of us need to be on the same page.”

“I can’t stop thinking about a national strategy. Mobilizing the people in the room, to bridge those collaborative relationships and mobilize in one direction. We need to get our arrows going in one direction. That’s the big lever to pull on. A national strategy would say to the country that this is a national issue to get some big movement.”

“We will need to unite the message. There’s a lot of communicators out there now, so how do we work together to make sure our messaging is consistent.”

Further, participants highlighted the importance of supporting people with FASD and ensuring their voice is heard and incorporated when developing new messages.

Participant quotes:

“We must integrate and build dignity into all aspects of work and life for people with FASD!”

“It will be important to find a way for society to become ok with people with FASD. I find people want to focus on working toward a world without FASD. That can be hurtful. So the message are important: we need to talk and become accepting of FASD, just like with ADHD and autism. We need a change in society.”

“We must always consult with individuals with FASD”

“It would be beneficial—whatever the next steps are—to have individuals with FASD involved along the way. It should be nothing about us without us.”

“Public messaging will be important. There’s a lot more awareness of FASD, which might bring more stigma. Combating this stigma will be “job #1”. Right now there’s a lot of blaming and shaming.”

Further, participants felt it was important to maintain the momentum of the symposium by ensuring everyone receives the written summary report. Moreover, many participants suggested the need for a lead organization that would continue to move the work forward.

Participant quotes:

“It will be important to find the knowledge keeper of [the symposium] information and take it to the next level”

“Do not lose the momentum...keep all of us informed and ask for our continued involvement”.

“We have a long way to go but together we can move forward”.

“All the ideas, looking at bringing them to us so we can go further. I’d like to see the ideas in the report. I’m excited about everybody’s ideas.”

“I had a role in supporting the resources needed for FWI, and was pleased to see how it captured our hopes, with regard to our expectations of the project. Now we will need to work on national collaboration.”

K. What barriers might get in the way of furthering the symposium work?

Many participants cited a lack of funding and resources as a significant barrier to future progress. Other barriers that were identified include a lack of leadership and a lack of political will.

Participant quotes:

“I feel a sense of urgency on this issue. We live and breathe this issue 24/7. I want us to move faster. But we have a big ship to steer.”

“I think that change is hard...Some thoughts [on messaging] are very entrenched, both in staff and people that work in the field, as well as the general public.”

“Some ideas will get dropped, it will be a matter of deciding which direction to take. This work needs to be staffed and resourced. It will need funding; it needs to be someone’s job to take it forward. Otherwise it will get forgotten about once everyone gets back to their home community.”

“Funding is always the issue. We need government bodies and decision-makers believing in the ideas. Because there are a number of governments to consider, as this is pan-Canadian work, and each province and territory has its own priorities and mandates.”

“No one taking the lead. We need strong leadership. HCMO is an amazing leader in Manitoba and our grassroots agencies work together, but provincial leadership is not there in other provinces/territories.”

“Knowing who all of the players are will be tricky. Communication among the group is important, and mechanisms will need to be in place for that. Change comes slowly, we’ll need to be patient. Political decision-makers might get in the way, things could get derailed if there’s a change in government, for example.”

“[We’ll] need three good ideas that the group likes and supports, a plan to operationalize the ideas, and resources to move the work forward.”

L. What assets might support further progress in FASD?

Many participants cited the CNFASD Partnership as a significant asset that could move the work of the symposium forward. Other assets that were identified include the Seeing the Spectrum report (2017) and the passion of FASD advocates. Importantly, participants cited funding, resources, and political leadership as important assets required for moving progress forward.

Participant quotes:

“We focus sometimes on all the work we have to do, but we’ve had gains and have helped a lot of people.”

“This is a really great group, that’s the biggest asset. The collaboration among provinces and territories is a great structure.”

“Collaboration. I was inspired by the room of national stakeholders. Everyone is working on the same issues. Very inspiring to have everyone together. The passion people bring, the advocacy dedication of the key stakeholders – it is amazing.”

“It is easy to feel hopeless because we don’t get the services that we need for families. Very challenging for many of us. I’m inspired to know there are people working on the issue, helps me keep going. It’s comforting to know they’ve got my back.”

“The Seeing the Spectrum report is an important foundational document. It will be good to have as the work moves forward.”

“Bringing this room together again will be important. Having practical tools and messaging guidelines.”

“Provinces that have done framing, like Alberta, have invested a lot of money into this work, and that’s the secret. It needs sustainable government-level funding. Non-profits can’t cobble together the financial support required to do this. A large philanthropic donation, or government support is needed.”

“We fund other academic research in FASD, including in prevention. That work could

align and support this work. It will be good to work preventatively with ground-breaking research and tools. And, its important for there to continue to be work that develops and provides resources and tools for people with FASD.”

“I think what needs to happen is more of a national strategy that can be implemented at the provincial or territorial level and then at then umm in communities but I think that leadership needs to come umm from above.”

M. Should anything have been done differently regarding the symposium?

Qualitative data from the evaluation survey and the key informant interviews provided important considerations that could inform future applications of the innovation engineering approach.

Participant quotes:

“I think that some of that fundamental explanations about what the goals were and what we wanted to come out with at the end of this were missing. So I think if some of that foundation had been clear at the beginning and maybe reinforced throughout, that would have been helpful.

“[The symposium] brought in the FrameWorks criterion, but it was disjointed. Maybe there could have been more of a theme, more of a deliberate way to guide the discussion. The tasks or activities could have been more connected. It seemed disjointed.”

I think the activities should have been timed and primed. A better cue to lead the discussion and more time for there to be organic dialogue.

Evaluation Summary:

Analysis of the survey and key informant interview data indicates that the symposium goals were achieved, as follows:

- a) *To bring together and engage a diverse group of national stakeholders to discuss and rethink the ways we talk about FASD, including the importance of promoting dignity with respect to FASD and alcohol use in pregnancy.* This goal was achieved per the analysis detailed on pages 21 and 22.
- b) *To help symposium participants gain a greater understanding of the reframing process.* This goal was achieved per the analysis detailed on pages 28 to 30 which demonstrates statistically significant gains.
- c) *To provide symposium participants with opportunities to contribute to the reframing of FASD in a meaningful way.* This goal was achieved per the analysis detailed on page 26.

- d) *To inspire symposium participants to take back an idea for reframing to their home communities and organizations for further reflection.* This goal was achieved per the analysis detailed on page 27.
- e) *To create initial ideas for the reframing of FASD that can be reviewed, assessed, and enhanced through the application of reframing research and the lessons learned from the Seeing the Spectrum report.* This goal was achieved per Appendix D.

Discussion and Limitations:

Some of the key limitations that emerged regarding the symposium include:

- **Evaluation Participation Rate**

The participation rate of the symposium evaluation survey was 58%. Alternative formats for survey completion (i.e. online option following the symposium), or additional time in table groups to encourage survey completion, may have encouraged higher participation.
- **Event Design**
 - Comments from both the survey responses and key informant interviews indicated that some of the activities, specifically some of the Day One activities (i.e. the Gauntlet exercise) were not sensitive to the sensory needs of participants with FASD. Although the Innovation Engineering process is designed to be fast-paced and to take people out of their comfort zones in order to spark new ideas, this had a negative impact on some participants' feelings of safety and ability to participate fully. A more inclusive event design may have considered alternative activity formats that were more accessible and FASD-friendly.
 - Some comments also reflected that more clearly identifying the event's end goals, perhaps using the themes identified by FrameWorks, could have more effectively connected the tasks and activities completed throughout the two days.

Many of the themes that emerged through survey responses and key interviews identified elements that are essential to the ongoing work of changing the conversation about FASD in Canada:

- It is essential that people with FASD are central in discussions about reframing moving forward.

- We need to continue to ensure there is a diversity of people and communities and cultural groups collaborating and continuing to have discussions about reframing FASD. Additional engagement with community and grassroots partners, diverse systems and sectors, and full representation from across Canada will be required to maintain momentum. This may include future meetings similar to this symposium.
- It will be important to strive toward a unified approach on a national level. Many respondents resonated with Nat Kendall-Taylor’s image having diverse individual messages, represented as ‘arrows,’ moving in one direction to create one consistent and unified national message. Respondents recognized that a unified approach will require resources (including funding, time, research, strategic planning, collaboration, knowledge translation, etc.) and the full buy-in and engagement of all stakeholders, in order to continue the work of reframing FASD across the country.
- Many people indicated that their most valuable take-aways from the Symposium were the concepts and recommendations for reframing identified by the *Seeing the Spectrum* report and Nat Kendall-Taylor’s keynote address. It will be important to ensure the reframing concepts introduced by FrameWorks and the *Seeing the Spectrum* report guide the work of reframing FASD and shifting public beliefs and attitudes across Canada.

Conclusion:

The symposium was successful in ensuring a wide range of representation of jurisdictions from across Canada, including representatives from all relevant sectors (e.g. justice, health, industry, education). Importantly, the symposium was successful in ensuring a balance in representation of both professional service providers and individuals with FASD, caregivers and parents, and community-based advocates. This effort in including as many as possible in ongoing work at reframing FASD will increase the success of making a large scale lasting positive change.

APPENDIX A: SYMPOSIUM AGENDA

Day 1

8:00 – 8:30	Registration, Light Breakfast & Networking
8:30 – 9:00	Welcome, Land Acknowledgement & Opening Remarks Opening Prayer and Address, Elder Dave Courchene Greetings from the Province
9:00 – 9:15	Opening Activity
9:15 – 10:15	Keynote Address: <i>Reframing FASD: Seeing and Moving Public Thinking</i> . Nat Kendall-Taylor, Chief Executive Officer, FrameWorks Institute
10:15 – 10:30	<i>Break & Networking</i>
10:30 – 12:15	Creating New Ideas: Mission #1
12:15 – 1:00	<i>Lunch & Networking</i> <i>Drumming by Cultural Advisor Debbie Parker</i>
1:00 – 2:45	Creating New Ideas: Mission #2
2:45 – 3:00	<i>Break & Networking</i>
3:00 – 4:00	Refining our Ideas
4:00 – 4:15	Closing Remarks

Day 2

8:00 – 8:30	Registration and Light Breakfast
8:30 – 9:00	Welcome and Opening Remarks, Review of Day 1
9:00 – 9:30	Introducing our Idea Categories
9:30 – 10:30	Building on our Ideas: Part 1
10:30 – 10:45	<i>Break & Networking</i>
10:45 – 12:00	Building on our Ideas: Part 2
12:00 – 12:45	<i>Lunch & Networking</i> <i>Drumming - FASD Life's Journey Inc.</i>
12:45 – 2:00	Building on our Ideas: Part 3
2:00 – 2:15	<i>Break & Networking</i>
2:15 – 3:00	Sharing of Ideas
3:00 – 3:30	Regional Working Groups
3:30 – 3:45	Next Steps
3:45 – 3:55	Closing Remarks
3:55 – 4:00	Safe Journey Prayer and Song, Elders Mary Maytwayashing and Debbie Cielen

APPENDIX B: BLUE CARD 1



Blue Card™



Name: How can we talk about alcohol use during pregnancy without judgment?

Narrative: *Tell the story of WHY it is VERY IMPORTANT that we focus energy on this Blue Card.*

The Narrative should be so clear that if employees get no further direction they will be motivated to work on this Blue Card and will know exactly what the Leadership's strategic and tactical intent is.

The public sometimes thinks that people who drink alcohol while pregnant don't care about their developing baby and are very different from them (process of "othering"). This means that people feel they can't or don't need to relate to those who drink alcohol during pregnancy.

A recent survey shows that Manitobans don't usually talk about things like trauma and poverty as reasons for drinking alcohol during pregnancy. Many people think alcohol use in pregnancy is an easy choice and comes down to willpower alone. There are many reasons why a person may drink while they are pregnant.

Research shows that stigma (fear of being judged) is the biggest reason why pregnant people who drink don't feel safe asking for help and accessing support services.

What does work is taking time to understand the whole person (their circumstances, life experiences, strengths) and supporting them in a positive, meaningful and dignity-promoting way.

Healthy communities have healthy pregnancies. It takes all of us to make this a reality.

Strategic Mission: *Finish the sentence with ONE mission, "We need ideas for _____"*

We need ideas that challenge and inspire Canadians to change the way they act, by thinking and talking differently about alcohol use in pregnancy.

Strategic Exclusions: *Ideas or types of ideas that we are NOT interested in.*

- We are not looking for new programs, services, or training.
- We are not interested in ideas or images that shame or blame people, or cause harm.
- We are not interested in ideas that ignore some of the root causes of alcohol use such as trauma, mental health, addictions, family violence, poverty, etc.
- We are not interested in ideas that see alcohol use during pregnancy (and addictions) as a 'simple choice.'
- We are not interested in ideas that focus only on pregnant people and ignore the family and community.

Tactical Constraints: *Design, time, resources, investment, regulations, people, etc.*

- Ideas must be completed between 1 day and 2 years, and cost between \$0 and \$250,000.
- Ideas must use respectful language and visuals (see Looking After Each Other Language Guide).
- Ideas must use plain language.

Exploration Areas: *Areas for stimulus mining when working to accomplish the mission*

- words, language, phrases, images & metaphors
- values and concepts (ex. Dignity; understanding life circumstances of people who drink in pregnancy; harm reduction; Indigenous knowledge and experience)
- ways to solve the communication challenges identified by the Seeing the Spectrum report, and ways to build on the report's 4 key recommendations (see this morning's handout)
- ways to present information (ex. Looking After Each Other video: "Meeting Women Where They Are At," "Girls, Women & Alcohol" blog: fasdprevention.wordpress.com)
- ways for groups to work together on related issues (ex. Bell Let's Talk; addictions & reproductive health)



Blue Card™



Name: How do we have conversations with and about people with FASD that are more strength-based, and better connected to larger disability conversations in Canada?

Narrative: *Tell the story of WHY it is VERY IMPORTANT that we focus energy on this Blue Card.*

The Narrative should be so clear that if employees get no further direction they will be motivated to work on this Blue Card and will know exactly what the Leadership's strategic and tactical intent is.

People with FASD have gifts and strengths, and should not be given labels such as ‘victim’ or ‘damaged.’

Research shows people are more successful (in relationships, in maintaining housing, in obtaining meaningful employment, etc.) when they are valued, treated with dignity, and given proper supports. For many people with FASD, this is not their experience.

Many national conversations about disabilities and mental wellbeing have successfully reduced stigma, but FASD is often left out of these conversations. FASD is sometimes seen as being very different from other disabilities (ex. Autism Spectrum Disorder). This may be because the cause of FASD is known, while the causes of other disabilities are not as clear.

We need the public to understand that FASD is an important focus in broader national strength-based conversations- such as other disabilities, mental health, stigma, addiction, and inclusion so that:

- the strengths of people with FASD are better understood
- quality of supports can be improved for everyone
- individuals, families, and communities impacted by FASD will be able to ask for what they need and have their voices heard

Strategic Mission: *Finish the sentence with ONE mission, “We need ideas for _____”*

We need ideas that challenge and inspire Canadians to focus more on the gifts and strengths of those with FASD, and that include FASD in broader national conversations about disabilities and well-being.

Strategic Exclusions: *Ideas or types of ideas that we are NOT interested in.*

- We are not looking for new programs, services, or training.
- We are not interested in ideas or images that shame or blame people, or cause harm.
- We are not interested in ideas that only talk about alcohol use and put blame on people for drinking alcohol during pregnancy.

- We are not interested in communication approaches that suggest people with FASD are victims, damaged or hopeless.

Tactical Constraints: *Design, time, resources, investment, regulations, people, etc.*

- Ideas must be completed between 1 day and 2 years, and cost between \$0 and \$250,000.
- Ideas must use respectful language and visuals must be used (see Looking After Each Other Language Guide).
- Ideas must use plain language.

Exploration Areas: *Areas for stimulus mining when working to accomplish the mission*

- words, language, phrases, images & metaphors
- values and concepts (ex. strength-based approaches; the concept of neurodiversity; valuing Indigenous knowledge and experience)
- ways to solve the communication challenges identified by the Seeing the Spectrum report, and ways to build on the report's 4 key recommendations (see this morning's handout)
- ways to present information ways for groups to work

APPENDIX D: PARTICIPANT SURVEY

1. I am a (check all that apply):

- | | | |
|---|--|--|
| <input type="checkbox"/> Service Provider | <input type="checkbox"/> Caregiver to a person with FASD | <input type="checkbox"/> Healthcare provider |
| <input type="checkbox"/> A person with FASD | <input type="checkbox"/> Alcohol industry representative | <input type="checkbox"/> Policy maker |
| <input type="checkbox"/> Researcher | <input type="checkbox"/> Communications / media | <input type="checkbox"/> Educator |
| <input type="checkbox"/> An Elder | <input type="checkbox"/> Other _____ | |

2. a) Did the Symposium meet your expectations?

- Yes No Unsure

b) Why or why not?

3. What did you like most about this event?

4. What did you like least about this event?

5. What is the main message you will take away from the Symposium?

6. Please rate the following components of the Symposium on how each helped create—or frame—new ways of thinking about, talking about, or understanding FASD and alcohol use in pregnancy (circle your response).

	Strongly Disagree			Strongly Agree	
a) Keynote address by Dr. Kendall-Taylor, FrameWorks Institute	1	2	3	4	5
b) Day 1 activities (mind mapping, spark deck, gauntlet)	1	2	3	4	5
c) Writing yellow cards	1	2	3	4	5
d) Day 2 activities (prototypes, pitching your idea)	1	2	3	4	5

7. Are there other people or groups of people (e.g. midwives, people from other disability groups) that would have been helpful to have at the Symposium? If so, please identify:

8. a) Did the Symposium inspire new ideas on how to address stigma related to FASD?

- Yes No Unsure

b) If yes, which ideas were your favourite?

9. a) Did the Symposium inspire new ideas related to alcohol use during pregnancy?

- Yes No Unsure

b) If yes, which ideas were your favourite?

10. Please rate the following statements (circle your response).

	Strongly Disagree			Strongly Agree	
a) I will take back an idea for reframing to my home community or workplace and discuss it with others.	1	2	3	4	5
b) I will be able to implement one of these ideas in my home community or workplace.	1	2	3	4	5
c) I was made to feel comfortable / safe to participate in the activities of the Symposium.	1	2	3	4	5
d) The attendees of the Symposium were diverse and represented many communities and peoples.	1	2	3	4	5

11. In your opinion, what are the immediate next steps to reframing FASD in Canada?

12. What will you do differently—if anything—because of what you learned at the Symposium?

13. How would you rate your knowledge of FASD, including lived experience and/or professional experience?

High

Medium

Low

14. Please rate any knowledge you gained from the Symposium.

	Low			High	
a) Before the Symposium, my knowledge on how to frame/reframe social issues was....	1	2	3	4	5
b) After the Symposium, my knowledge on how to frame/reframe social issues is...	1	2	3	4	5
c) Before the Symposium, my understanding of the importance of reframing FASD and alcohol use in pregnancy in order to promote dignity was...	1	2	3	4	5
d) After the Symposium, my understanding of the importance of reframing FASD and alcohol use in pregnancy in order to promote dignity is....	1	2	3	4	5

15. Please share any other comments about the Symposium.

APPENDIX E: KEY INFORMANT INTERVIEW GUIDE

Question 1: What were your overall impressions of the symposium?

Question 2: Did the symposium meet your expectations?

Question 3: How is this symposium different to other event that you have attended?

Question 4: Do you think that the different activities that were used made a positive impact on the symposium?

Question 5: Did you feel your point of view was valued?

Question 6: In your opinion, what are the next steps to reframing FASD in Canada?

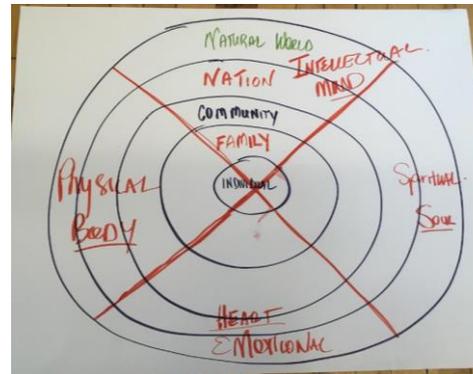
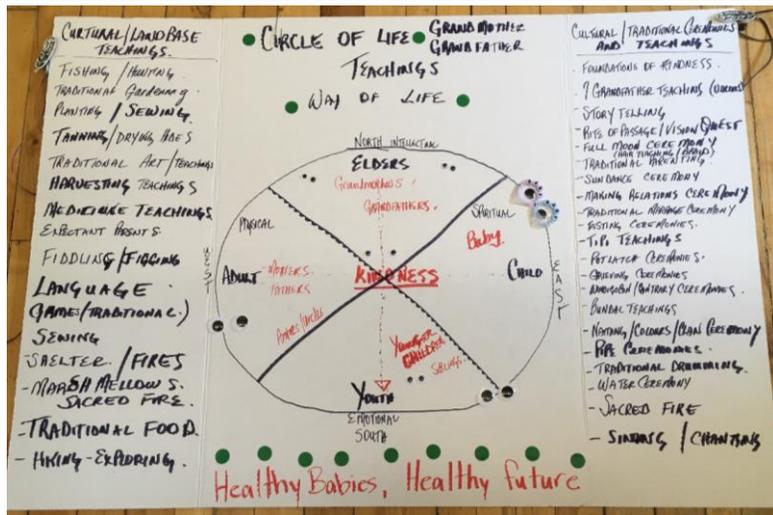
Question 7: In your opinion what are some of the things that might get in the way of some of these next steps?

Question 8: In your opinion what are some of the things that might help in some of these next steps?

Question 9: Any other comments?

APPENDIX F: IDEA PITCHES FOR REFRAMING BY SYMPOSIUM PARTICIPANTS

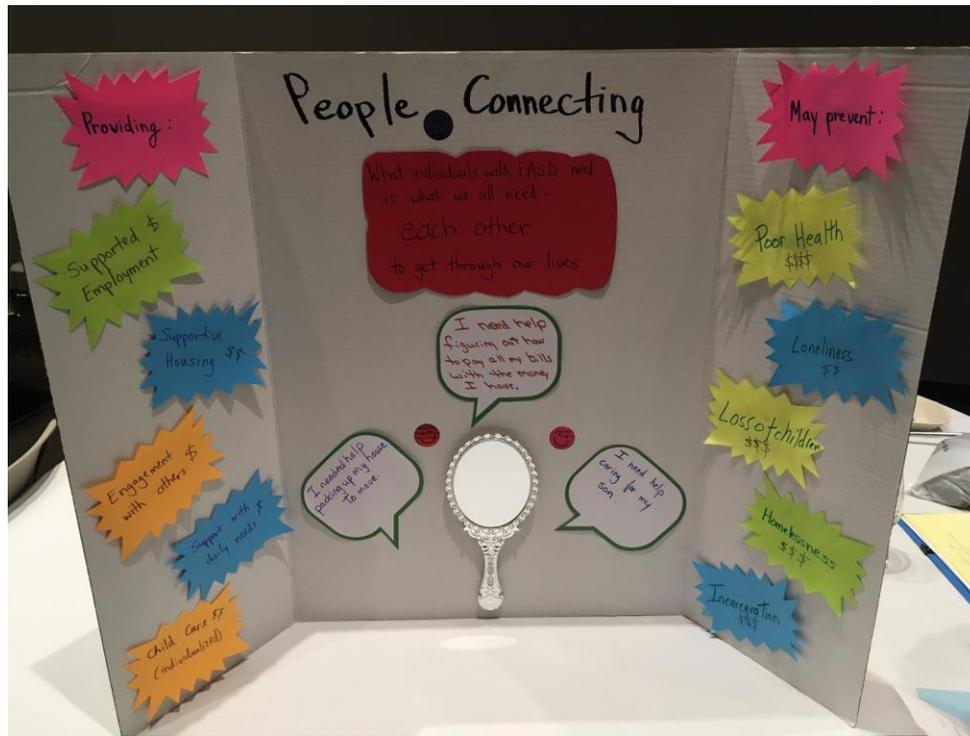
Theme (Alphabetical Order)	Pitch	Pitch Summary
Community mentoring	1. Circle of Life Teachings	This pitch highlights the importance of using traditional Indigenous Teachings when supporting individuals, families, and communities across the lifespan, including pregnant women and people with FASD. Land-based Teachings are emphasized as an evidence-based best practice, in particular to engage at-risk youth. The approach would allow people to begin to access mentorship from Elders and community leaders at “any age and any stage.” The pitch envisions a nationally accessible toolkit that would provide a framework on how to get started in using this approach to service, with champions available to support individualization for each community.



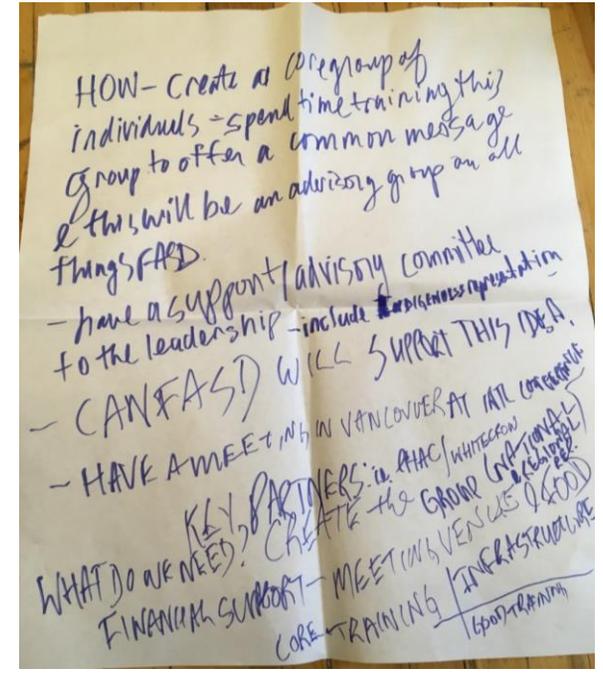
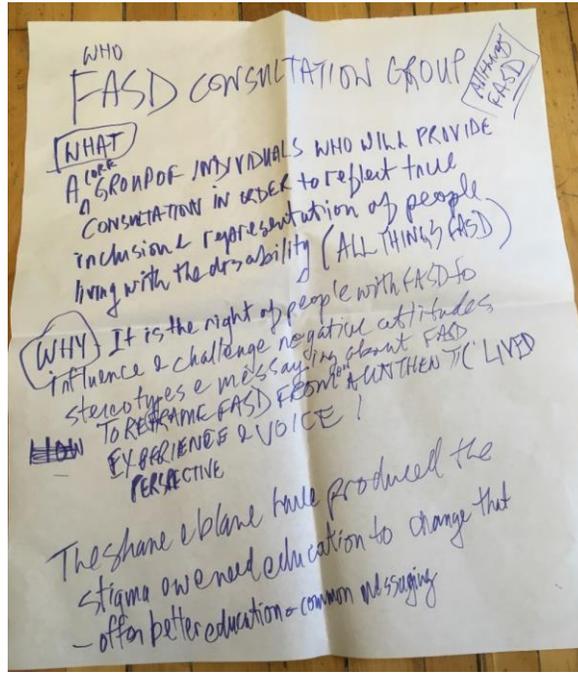
Theme (Alphabetical Order)	Pitch	Pitch Summary
Community mentoring	2. New Beginnings	Emphasizing the importance of mentorship and relationships, Indigenous doulas are paired with pregnant women to address their needs holistically - including promoting good nutrition, prenatal care, education, addiction support, and mother-child bonding. These strategies would improve outcomes for pregnant women and babies. The support approaches would be based on the Seven Sacred Teachings, Medicine Wheel Teachings, dignity, love, respect, balance, wellness, and inclusivity of all cultures. This approach could be expanded within current programs and/or promoted nation-wide.



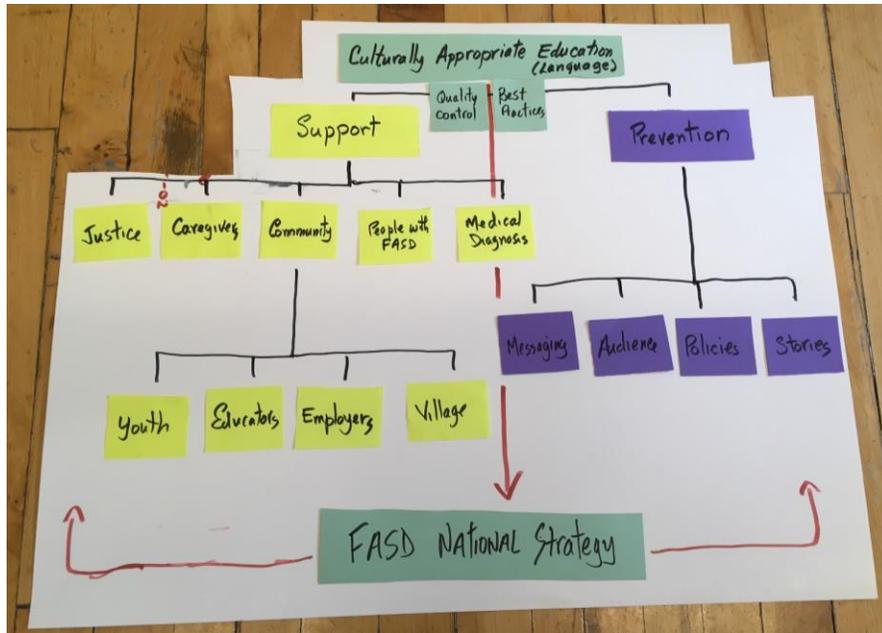
Theme (Alphabetical Order)	Pitch	Pitch Summary
Community mentoring	3. People Connecting	This pitch aims to challenge the notion that everyone needs to be 100% independent, instead, it conveys that we all need each other. People are encouraged to reflect on times that they needed support themselves, in order to normalize that it is okay to need supports. A message is made to the public and to government that people have better outcomes (which saves taxpayer dollars in the long run) when they have comprehensive supports such as supported employment, supportive housing, child care, and parenting support.



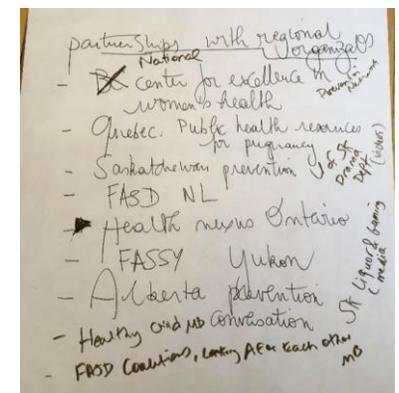
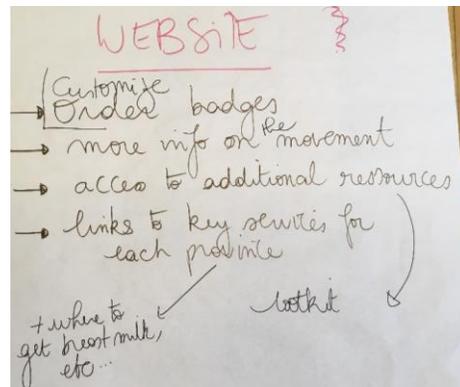
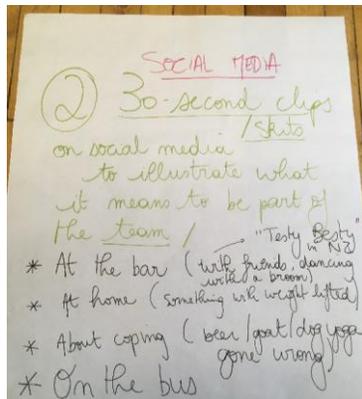
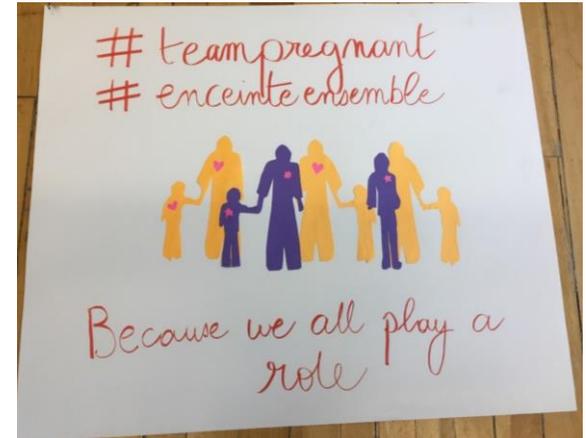
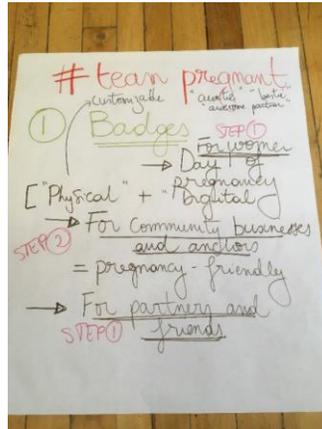
Theme (Alphabetical Order)	Pitch	Pitch Summary
Consulting with People with FASD	4. FASD Consulting Group	A group of people with FASD who can provide consultation to the “FASD field” on things like training, advertising, conferences, and messaging to ensure the perspectives of people with FASD are well-represented. If misinformation within the field is corrected and a unified message is established, the FASD field can communicate more effectively with the public. The consulting group would provide the “big picture” perspective on why reframing FASD is important.



Theme (Alphabetical Order)	Pitch	Pitch Summary
Education	5. Culturally-appropriate Education	This group identified that certain regions of Canada have more access to FASD educational materials than others. This pitch proposes to close the gaps of knowledge and expertise between different provinces and territories through an online repository of educational tools, resources, and supports for trainers and educators. A vetting process would ensure high quality best practices that are accurate and non-stigmatizing; people with FASD would also have voice and influence on what is included. This repository will ensure that FASD trainers and educators are providing high-quality, culturally appropriate, and respectful information.



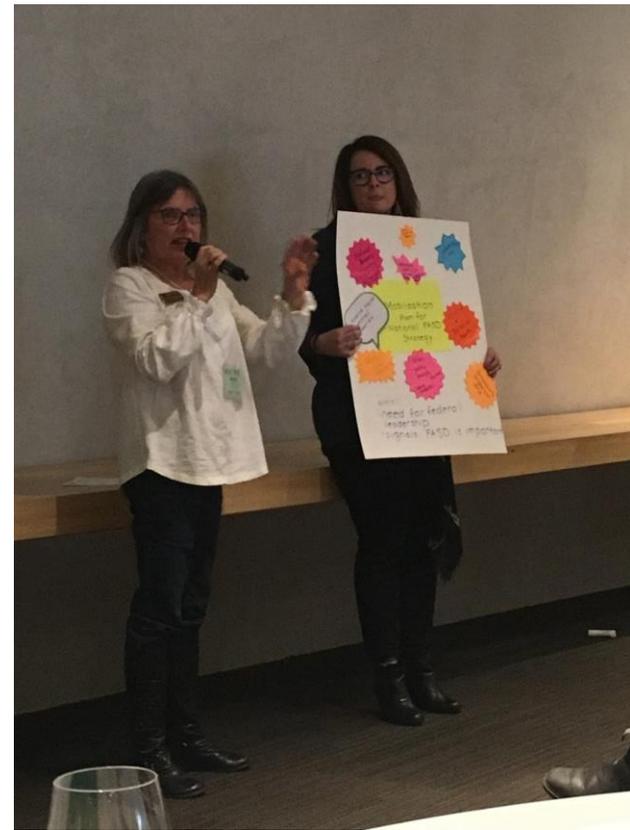
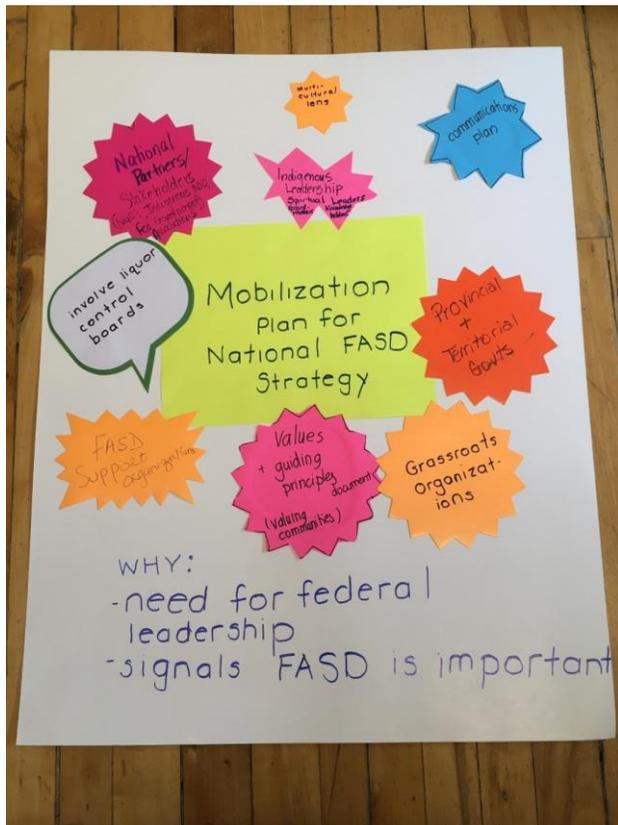
Theme (Alphabetical Order)	Pitch	Pitch Summary
Messaging	6. #team pregnant #enceinte ensemble ...because we all have a role to play	A messaging campaign that promotes the role of community in supporting healthy pregnancy. Badges would be created that people wear to signify they are supporting a pregnant person (partner, family member, friend, etc). A hashtag (#teampregnant/ #enceinteensemble) would link to online resources, including short humorous videos showing how to support healthy pregnancies. Existing FASD organizations across Canada could partner with the campaign. A second phase could use badges to identify safe spaces for pregnant women



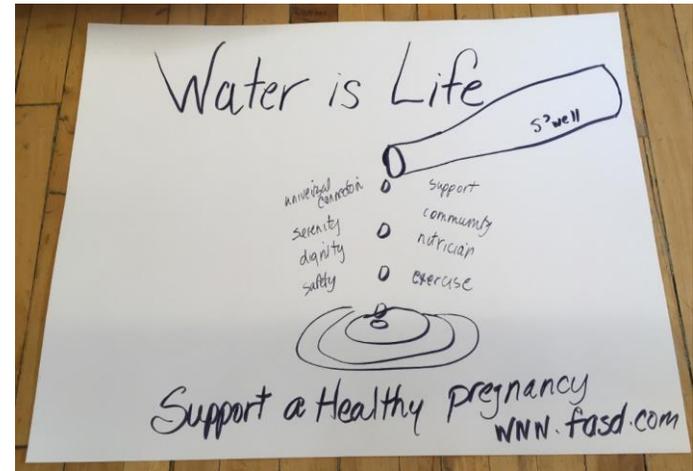
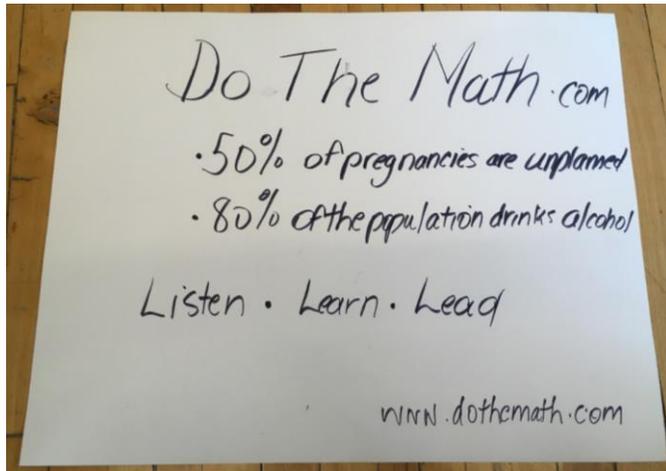
Theme (Alphabetical Order)	Pitch	Pitch Summary
Messaging	7. Paper Quilt: We are all community members	This pitch aims to build community by breaking down “othering” of people with FASD. FASD organizations could work with a group of children with FASD and a group of children without FASD to collaborate, build inclusion, and learn from each other while making a paper quilt. A poster could be made of the quilt with the title, “We are all community members.” Multiple quilt projects could be undertaken.



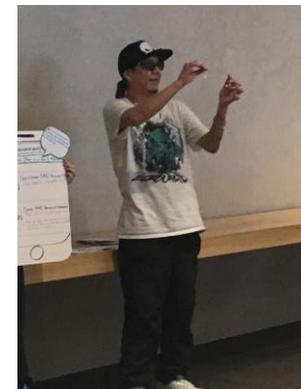
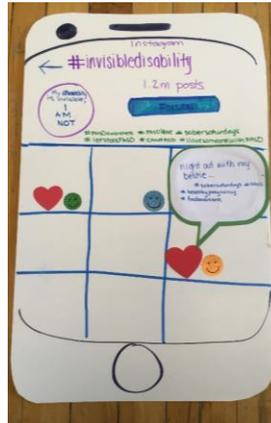
Theme (Alphabetical Order)	Pitch	Pitch Summary
National FASD Communications Strategy	8. Planning for a National FASD Strategy	This pitch addresses the goal of cohesion moving forward with unified values and principles. All FASD stakeholders in Canada would be identified and included- stakeholders, NGO's, government, Indigenous leadership, grassroots organizations, caregivers, the liquor industry, and other disability organizations. A multi-cultural lens would be employed. A communications plan would promote one unified message. This pitch aims to convey to Canadians that FASD impacts us all.



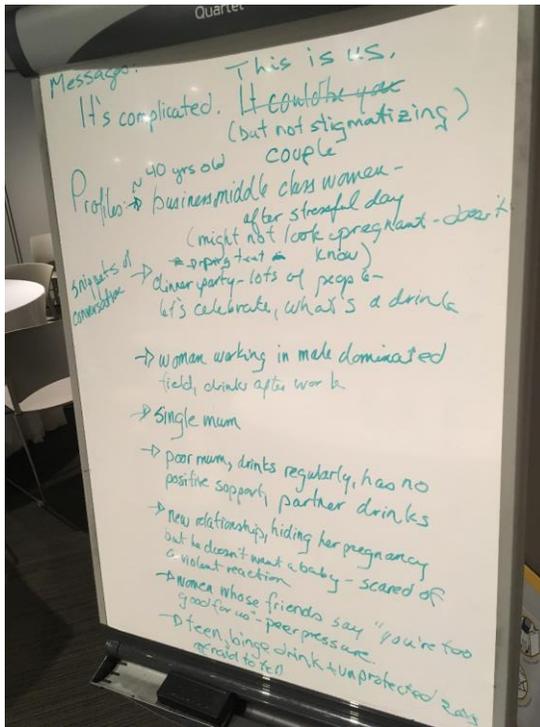
Theme (Alphabetical Order)	Pitch	Pitch Summary
Public Awareness Campaigns	9. "Do the Math.Com" & "Water is Life"	<p>"DoTheMath.com"</p> <p>Challenges the message that FASD is "100% preventable" and encourages a different approach, moving away from shaming and blaming women who drink during pregnancy. The campaign would focus on normalizing alcohol and unplanned pregnancy, and emphasizing that FASD impacts all of us, and we all need to have conversations about FASD. The ad would state that 50% of pregnancies are unplanned, and 80% of the population drink alcohol. The campaign would direct people to a website for more information.</p> <p>"Water is Life"</p> <p>This campaign would feature a water bottle with drops of water dripping out. Each drop would have a different title of a way to support healthy pregnancy-universal connection, serenity, dignity, safety, support, community, nutrition, exercise, etc. On the campaign's website, people could click on the drops to learn more about each category. This campaign emphasizes holistic wellness, and could link to strategies on nutrition, substance use, etc. FASD organizations across Canada could use this campaign to create consistent messaging.</p>



Theme (Alphabetical Order)	Pitch	Pitch Summary
Social Media	10. #invisibledisability	This pitch aims to establish a platform that creates national connection. Individual FASD initiatives would still be celebrated locally, but would all be linked together nationally. The hashtag #invisibledisability would be used to connect on Facebook and Instagram. Print advertisements featuring a blank speech bubble, with the hashtag written underneath, would pique interest and encourage people to look up the hashtag, which would link them to resources on FASD. Clear ribbons would be a national symbol for the campaign.



Theme (Alphabetical Order)	Pitch	Pitch Summary
Storytelling	11. "It's Complicated/This is Us"	This pitch would create a documentary-style video profiling several different pregnant people, showing the wide range of experiences people have in pregnancy, and the complexities of each person's life. The pitch emphasized the importance of ensuring that the stories are told in non-judgmental, non-stigmatizing ways.



Theme (Alphabetical Order)	Pitch	Pitch Summary
Storytelling	12. Fabric of Life	<p>This idea emphasizes the interconnectedness of our stories, and reinforces the notion that having conversations about FASD is the role of the whole community- not solely pregnant women and people with FASD. This will counteract tendencies of “othering,” and allows everyone to see themselves in the context of a larger community story. The pitch entails a community undertaking a weaving project. Community members would weave fabric as they tell their story, in their own language. Stories may cover topics such as community, pregnancy, and raising children. When one person’s story finishes, another person would take over the weaving and begin telling their story. There would be visual representation of having a variety the community’s stories come together into a braid- emphasizing the strength in connectedness.</p>



APPENDIX G: SUMMARY OF THE SEEING THE SPECTRUM REPORT

Summary of the [Seeing the Spectrum Report](#) (FrameWorks, 2017)

- FrameWorks Institute found that the public does not always understand FASD and alcohol use in pregnancy the way that experts (people with FASD, people who use alcohol in pregnancy, and people who support them) would like.
- This leads to **stigma** (negative feelings and shame) towards people with FASD and towards women who drink alcohol in pregnancy.
- If we can change the way that Canadians think about FASD and increase public understanding, we can talk about, address, and prevent FASD in more effective ways.
- The table below outlines seven central topics of the report. For each topic, FrameWorks analysed 1) How the public thinks about FASD 2) What the public needs to understand, and 3) How we can help the public understand and use this information

Topic 1	How the public thinks about FASD	What the public needs to understand	How we can help the public understand/use this information
What causes FASD	<p>-The public thinks that a woman chooses to drink alcohol when she is pregnant because of poor control or lack of will power.</p> <p>-The public thinks that alcohol always affects a fetus' development in the same way, but it is up to fate (or luck) whether the child gets FASD or not.</p>	<p>-There are many reasons why a person might drink alcohol in pregnancy.</p> <p>-Alcohol affects every person's body and every pregnancy differently, based on many factors.</p> <p>-There is no known safe amount of alcohol use in pregnancy.</p>	<p>-We need to talk about FASD in a way that explains important social factors that may lead to alcohol use in pregnancy (such as addiction, lack of support, trauma, mental illness, etc.).</p>
Topic 2	How the public thinks about FASD	What the public needs to understand	How we can help the public understand/use this information
Who is affected by FASD	The public sees FASD as mostly a problem for poor and Indigenous communities.	<p>-FASD can occur in any community where alcohol exists- no matter a person's income, culture, race, or ethnicity.</p> <p>-FASD has impacts for ALL of society, not just the individuals immediately affected.</p>	<p>-We need people to understand that FASD and alcohol use in pregnancy can impact anyone and always impacts everyone.</p> <p>-In communities where addiction, poverty, and trauma are common greater understanding and support is needed.</p>
Topic 3	How the public thinks about FASD	What the public needs to understand	How we can help the public understand/use this information
Women's life circumstances in pregnancy	The public thinks that once a woman becomes pregnant, her life is all about her pregnancy, and it is her responsibility to make the decision to stop drinking right away. If she doesn't, she is seen as a weak or bad person.	A woman's life history and realities don't simply disappear when she gets pregnant- any reasons she drank alcohol before pregnancy still exist, and may lead to drinking alcohol in pregnancy.	<p>-We need people to understand the many reasons why people drink alcohol, including during pregnancy.</p> <p>-It is important that pregnant women are not seen as selfish or not caring for their unborn child if they consume alcohol.</p>

Topic 4	How the public thinks about FASD	What the public needs to understand	How we can help the public understand/use this information
Stigma towards women who drink in pregnancy	The public believes that making women feel shame and blame for drinking in pregnancy is effective in reducing alcohol consumption during pregnancy. It will keep pregnant women from drinking.	Shame and blame keep pregnant women from seeking support for alcohol use, because they don't want to be judged. Getting rid of stigma will help us prevent and address FASD.	We need to shift people's thinking away from blaming individuals who drink in pregnancy, and towards looking at "big picture" factors, like addiction and mental health, as causes of FASD. We need to shift from blame and punish to heal and support.
Topic 5	How the public thinks about FASD	What the public needs to understand	How we can help the public understand/use this information
The role or culture of drinking in society	-The public sees drinking as a choice that an individual makes and for which they are solely and completely responsible. -This prevents people from seeing the need to change social values about alcohol use or do other things in order to prevent FASD.	-Canada has a way of understanding drinking that sees alcohol use as very normal for most people- but pregnant women who drink are judged. -There are norms and values that need to be changed to prevent FASD.	-The public needs to recognize that when alcohol use is normal and encouraged in society, this is going to affect women who are pregnant. Efforts to prevent alcohol use in pregnancy must address Canada's drinking values and culture.
Topic 6	How the public thinks about FASD	What the public needs to understand	How we can help the public understand/use this information
How FASD impacts the brain	The public believes that if you have FASD, your brain is damaged, and nothing can be done.	-Brains change in response to our experiences throughout our whole life. This is called "plasticity". -When people with FASD know their strengths and challenges, they can understand what supports they may need, and how to tell others how to support them.	-We need the public to hear about carefully thought out and positive approaches that work to support people with FASD. -We need people to understand that when we work together in practical ways to support people with FASD we can make a difference. Positive change is possible!
Topic 7	How the public thinks about FASD	What the public needs to understand	How we can help the public understand/use this information
Who is affected by FASD and alcohol use in pregnancy, and who is responsible for solutions	-The public thinks that the only people affected by FASD are those with FASD and those who drink during pregnancy. -The public thinks that only women who drink during pregnancy are responsible to prevent FASD. -The public thinks that only people with FASD are responsible to improve their lives.	-Alcohol use in pregnancy and FASD are "big picture" <i>system</i> issues that affect everybody. -All Canadians have a role to play in supporting women who use alcohol in pregnancy, and people with FASD, such as: <ul style="list-style-type: none"> • Following the calls to action of the Truth and Reconciliation Commission, • supporting women to have healthy pregnancies, and • addressing "big picture" issues like racism, trauma, violence, and stigma. 	-We need people to understand that the impacts of FASD affect our whole country. We all benefit when pregnant women and people with FASD are well supported. -We need people to understand that FASD is everyone's concern, not just an individual matter. We need to move from individual blame and responsibility to collective solutions and social responsibility. -We need everyone to understand they have a role in preventing FASD and supporting people who have FASD.