

Final Report: 2015 Coalition of Chairs Annual Gathering  
Prepared by: The DPP Working Group  
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On May 28<sup>th</sup> and 29<sup>th</sup> the Healthy Child Manitoba Office (HCMO) hosted the Coalition of Chairs Annual Gathering. Once again this year, in addition to the coalition chairs, several active members of the FASD community were also in attendance. In total, 36 participants attended the gathering. The gathering was facilitated by the members of the Dignity Promotion Project (DPP) working group, with assistance on Day 1 from the members of the Common Language Subcommittee. The central theme for the gathering was promoting dignity for Manitobans affected by FASD; however teambuilding within the Coalition of Chairs was built into the afternoon of Day 2.

### Overview of Activities

#### Day One

##### Welcome and Opening Ceremony

The gathering began with Elder Velma Orvis leading the group through an Opening Ceremony and Smudge to help participants clear their minds and ready themselves to focus on FASD over the next two days.

##### Recap of DPP

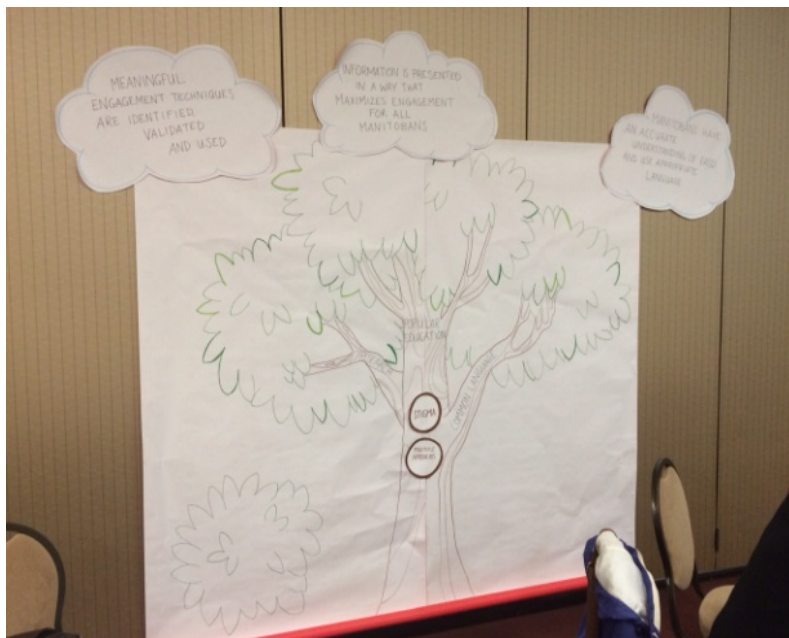
Holly Gammon provided participants with a history of the FASD coalitions and the annual Coalition of Chairs gathering:

- Coalitions began as grassroots groups who shared an interest in FASD
- HCMO began funding annual coalition gatherings in 2007.
- After a few years HCMO began to be questioned about what they should be doing, what their purpose was.
- So, in 2013, the gathering focused on community capacity building with guest speaker Dr. Rick McCutcheon. This presentation spurred a lot of enthusiasm and discussion.
- In 2014, Dr. Rick McCutcheon came back again and facilitated the gathering. There were opportunities to get to know one another better, to work on a vision for the future and to do activities addressing diversity and 'othering'.
- After the gathering, a working group reviewed everyone's feedback and a common theme emerged; the need to address the stigma surrounding this disability. Working from this common theme, a working name was created; The Dignity Promotion Project (DPP) and a structure for moving forward was developed; three pillars: Common Language, Research, and Popular Education.
- Holly introduced the working group members
- DPP participants met via go- to-meeting in September and December. The theme and three pillar structure were discussed and approved by the group and subcommittees were created for each pillar. DPP members can volunteer to join a subcommittee that interests them.

Holly explained that the coalitions have not been lost in this process of working on the DPP. HCMO will make sure to allot time during gatherings that is specific to the coalition members. Holly also explained that coalition members are central to the success of the DPP, as they are the change agents in this social justice project; they will take the lessons learned, the projects produced to all corners of the province.

## DPP Moving Forward

Holly finished off by explaining how the DPP project will continue to move forward. Each year when we gather, the DPP working group will bring you ideas and activities for you to provide us with feedback on. This data/information helps to inform us about what is happening and what needs to change, how that might happen, where and when it could happen. The working group and subcommittees study the data – they come up with draft plans. These draft plans are brought back to the larger group –discussion happens. The working group and subcommittees take the discussion and make changes, add new ideas, make tweaks, and bring it back for further discussion....and the process continues.



## The Dignity Tree

Throughout the two days, there was a tree on the wall with some leaves and clouds posted up. Holly explained that the trunk of the tree is called Dignity and the three branches are called: Common Language, Research, and Popular Education.

The bottom leaves are the current state of dignity in Manitoba (taken from what we heard at last year's gathering). The clouds are our ultimate

visions for people living with dignity (also taken from last year). Participants were asked to think over the next two days about how we are going to get from the bottom of the tree to the clouds.

## The Name Game

Participants sat in a circle with the rest of their table group. They took turns sharing their name with the rest of the group and any important information or stories regarding their

name (e.g. how they came to have that name, what their name means, any nicknames they have, etc.). This activity helped the group to reflect on the importance of a name.

### **D-I-G-N-I-T-Y what does it mean to you?**

Five stations were set up around the room with flip chart paper and a key question per station:

- 1) What does dignity mean to you?
- 2) What helps build your own sense of dignity?
- 3) Who has the power to increase/decrease your sense of dignity?
- 4) Why is dignity important?
- 5) Share your story of witnessing dignity

Participants had three minutes at each station to answer the questions. Next, participants were invited to tour each station to read everyone's responses (Appendix 1). Afterwards, everyone took part in a large group discussion to share their thoughts on what they just read.

### **Provincial FASD Awareness Survey**

Kathy shared findings from a recent survey conducted by HCMO gauging the awareness and perceptions of alcohol use in pregnancy within Manitoba. The audience participated in the presentation by reflecting and offering interpretations on the results.

The full 32 page report is available by emailing: [kathy.andrew@gov.mb.ca](mailto:kathy.andrew@gov.mb.ca)

### **Subcommittee Updates**

Brenda Elias provided an update on the Research Pillar subcommittee:

- The research group is working on an application for a SSHRC Partnership Grant as well as a CIHR grant. The research itself will focus on the social components of the lifelong experience of living with FASD through a variety of lenses and will promote both practical tools and knowledge focused on enhancing system and community responses to empowering and embracing those affected by FASD. The lenses include:
  - A trauma informed lens
  - A family/caregiver lens
  - A systemic pathway lens
  - A community engagement lens
  - A cultural humility lens.

Holly Gammon provided an update on the Popular Education Pillar subcommittee:

- The Popular Education subcommittee has gotten off to a little slower start than had originally been anticipated. Part of this is due to some membership changes but it is largely due to the realization that this subcommittee is really our Knowledge

Translation pillar and very careful thought needs to be put into all information that is put out into the public. A decision was made to slow things down a little while more is learned from the Frameworks Institute and from the common language subcommittee. The subcommittee will start up again in the summer with some additional funding, additional members and some new ideas.

Ken Lamoureux, Erin Klimpke, and Colleen Tower provided the following update on the Common Language Pillar subcommittee:

- The subcommittee has met 5 times over the winter and spring.
- Members decided that the first step towards creating a common language is to get all DPP members to agree on what that language is and begin using it in their work
- The subcommittee has also started working on a common language guide and has completed a media scan in order to get a sense of the language being used by the media to describe FASD. The subcommittee will share more on these two projects at a future gathering.

### **Frameworks Presentation**

Jill Isbister presented on a not for-profit organization in the US called The Frameworks Institute, who specializes in developing communication approaches that change the way the general public views social issues. They have worked internationally, including recently in partnership with an organization in Alberta on the topics of addiction and child mental health. Their work aims to help people understand complex issues deeply and quickly so they integrate this new information into their understanding in the same way experts understand it. This is what they call framing. Key elements to a good frame include keeping it thematic (not focussed on one individual), including values that are commonly shared by society, using metaphors to illustrate clearly how the issue works and focusing more on solutions than the problem (people rarely need convincing that social issues are a bad thing).

The method Frameworks uses to create their approach is in 3 parts:

- 1) How is it now? This involves a news media analysis and one on one interviews with the general public to see how they view an issue,
- 2) Where can we change? This includes expert interviews to determine where the general public is similar and different from the science of an issue. They call this "Mapping the Gap" where the biggest gap in understanding points to where you want to target your communications
- 3) Create and test the new frame. This involves testing metaphors, values and visuals to see which frame will work best. As well, experts are engaged to see if they find the new frame easy to use.

In summary, Frameworks says:

- People put new information into existing boxes or old ways of thinking.
- Frames can redirect thinking to a different, more productive box.
- Our stories need to tell social solutions, not individual ones

- We should share our solutions up front and in a united way
- Be persistent – this kind of change takes time.

For more information, and to see some of the videos Jill showed, visit the Frameworks website. The main page is: [www.frameworksinstitute.org](http://www.frameworksinstitute.org). The PowerPoint that Jill referenced is found at: <http://sfa.frameworksinstitute.org/> and provides more detail on what was presented.

She also showed two other videos at these links:

- <http://www.albertafamilywellness.org/resources/video/how-brains-are-built-core-story-brain-development>
- <http://www.frameworksinstitute.org/canada-child-mental-health.html>

## **Mapping the Gap**

DPP members participated in small group discussions, which were facilitated by Common Language subcommittee members. The purpose of these conversations was to begin “mapping the gap” between what the experts (knowledgeable caregivers and service providers) know about FASD and what the general public views/understands FASD.

The Common Language subcommittee collected all of the feedback from the small group discussions and will review it at their next meeting.

## **Naming Discussion**

Elder Velma Orvis was invited to help everyone to better understand the process involved in a naming ceremony. Velma provided information on what a naming ceremony is, how it happens, how a naming ceremony would fit well for this project and some examples of naming ceremonies she has provided in the past. DPP members asked several questions and there was a good discussion. On day two, at the end of the meeting, members were asked to vote on whether they would like to have a naming ceremony for the DPP.

## **Day Two**

### **Squiggle Birds and Drawing Toast**

Brenda Elias led the group through two drawing exercises. The first exercise (Squiggle Birds) helped everyone to understand that our brains are flexible and that we need very little information to organize and assign meaning to images.

The second exercise (Drawing Toast) helped everyone to understand that every process has a start and an end. How you get there can be very different/personal, however we all arrive at the same conclusion (drawing a picture of how to make toast). The group saw the DPP as a similar process. We know what we have and where we want to end up. We need to share all our versions of the story of how we arrive there, respecting that each person’s path will be different, however still getting to the same conclusion.

## A Conversation about Evaluation

Kathy Andrew and Javier Mignone led a discussion with participants about what it meant to include an evaluation of the DPP (Appendix 2)

## Pruning the Future



Jill Isbister and Lisa Balcean used the Dignity Tree to lead the group through a planning exercise to determine how to get from the bottom of the tree (the current state of dignity in Manitoba) to the clouds (our ultimate visions for people living with dignity).

Each person was invited to write 1 idea per leaf. Then place it on the tree, moving closer to the top as the idea seems closer to the final vision. If a leaf did not seem to fit on an existing branch, it was

placed on the bush at the bottom of the tree. The leaves represented action items, solutions, or end products that were seen as steps along the way.



Once all of the leavers were on the tree, the group worked on pruning the tree. All of the leaves were reviewed and then sorted into common themes and were moved up or down the tree based on where they fit within the final vision.





The DPP working promised to take the Dignity Tree back and put it into a more usable, traditional format of a timeline for implementation, which will serve as a guide for the branches (pillars) for the next few years (Appendix 3).

### **Wrap up of DPP Activities**

Holly Gammon asked participants to provide feedback by answering four questions on recipe cards.

### **Presentation by Dr. Ana Hanlon-Dearman**

Dr. Hanlon-Dearman provided an update on the new Diagnostic Guidelines for FASD, which will be released in the summer.

### **Coalition Networking**

Coalition members participated in a sharing circle activity. Participants took turns introducing themselves, letting others know what coalition they represented, and then provided updates on what their coalition has been doing over the past year and what their plans are for 2015/16.

After everyone had a turn to share, Ken asked participants to answer three questions on recipe cards. Ken also shared an updated coalition contact list and a map of where all of the coalitions are located throughout Manitoba (Appendix 4).



## Appendix 1

### Data from the D-I-G-N-I-T-Y Exercise

#### **What helps build your sense of dignity?**

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- Knowing who I am
- Self-worth/ Self-respect
- Being understood by others
- Knowing your history/roots
- Sense of belonging and being accepted
- Strong social and life skills
- Shared understanding
- Practicing a healthy lifestyle
- No label
- Feeling of safety
- Horizontal relationships
- Inclusion
- Security
- Commitment
- Reassurance
- Support
- Avoid double standards
- Spirituality
- Advocate
- Allies
- Compassion
- Respect of Others
- Consistency of positive
- Community understanding or respect
- Knowing what dignity is
- Acting with dignity
- Identity and culture
- Being a role model
- Connection to others
- Love
- Acceptance
- Physical appearance
- Age
- Confidence
- Title
- “Walk the talk”
- Family
- Groups like this
- Positive support
- Like-minded and open folks
- Understanding
- Differing perspectives
- Teamwork
- Social environment
- Legislation
- Equity
- Personalized modifications
- Flexibility
- How I am welcomed
- Compassion and kindness
- Forgiving and receiving forgiveness
- Maintaining balance (4 areas of medicine wheel)

## Why is dignity important?

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- Feel human
- Respected
- We all have it (inherent) but may not feel it
- Forms basis for relationships
- Creates equality → the golden rule
- Helps to have and maintain self worth
- Takes strength to feel dignity when you're not being treated with dignity
- Helps to shape your identity
- Equality
- Inherent of humanness
- Helps you to be creative
- Gets best out of people
- Better working relationships
- Creates bridges, creates inclusiveness
- Eliminates stigma
- Promotes understanding and compassion
- Empowering
- Enables to do better and grow
- Promotes altruism
- Having dignity helps others with dignity
- Trustworthy
- Upward mobility
- Social justice
- Empowerment
- Self actualization
- Caring
- Human rights
- Societal wellbeing
- Peace within (between)
- Overall community wellness
- Humanness (self-actualization)
- Self-worth
- Closest connection to higher spirit self

## **Who has the power to increase/decrease your dignity?**

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- Anyone if you let them → VERY IMPORTANT
- People in positions of power or you feel have power
- Yourself, spouse, family, community, all society!
- Our children
- Friendships
- Grandchildren
- Grandparents
- Ancestors and future generations
- People in authority (i.e. police)
- Teacher
- Religion and beliefs
- Education and knowledge
- Clothing
- Culture
- Writers, movies
- Employers
- Churches/religion
- Government
- Medical system
- School systems
- Business people
- Architecture
- “normal people”
- Ethnic groups
- Traditional genders
- Administrative roles
- Youth
- Men
- Media
- History
- God/creator
- Nobody and everybody
- Sports
- Pop culture
- Social media
- Ads
- Posters
- Self
- Government/leadership
- Media
- Individualistic mentality
- Party leadership

## What does dignity mean to you?

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- Equality
- Authentic
- Genuine
- Respect
- Real
- Satisfying
- Well-being
- Self-esteem
- Love for on another
- Protecting your pride
- Kindness
- Humanity
- Respect
- Honoured
- Valuing
- Proud
- Inclusion
- Acceptance
- Success
- Understood
- Full potential
- Confidence
- Informed
- Diversity
- Support
- Access
- Free of oppression
- Joy
- Nobility of spirit
- Grace
- “doing the best in the moment”
- Equity
- “nobody’s perfect”
- Respect
- Honouring
- Humility
- Barrier-free understanding  
(simple language)
- Being proud of who you are!
- Knowing your self-worth
- Living life with honor
- Being yourself in any  
circumstance and feeling  
comfortable in your own “skin”
- Basic rights
- Empathy
- Compassion
- Proud to be aboriginal
- Being strong, standing your  
ground

## Appendix 2

### **A Conversation about Evaluation**

Kathy Andrew and Javier Mignone led a discussion about what it meant to include an evaluation of the Dignity Promotion Project. We began the session by introducing the topic:

“We want to engage with you, the members of this project, throughout the five years we have in this project. These points of engagement won’t just be a courtesy check-in with you, rather we’ll be relying on you to help us understand the ‘data’ that comes to us through the different aspects of the project. You will be tasked with interpreting that data – like you did yesterday with the Awareness Survey. That was our first glance at what data analysis can look like in this interactive, engaging, process evaluation. You will also generate the data at times – like you did yesterday when you answered questions at your tables, giving your expert perspective on the topics in order to contrast with the general public’s understanding at a later time.”

‘Data’ will come from many places:

1. External data – e.g. Awareness Survey
2. Sometimes you will be creating the data
3. Research Pillar
4. Common Language Pillar
5. Popular Education Pillar
6. Other places

We then opened it up to the audience to hear what they would like to see in an evaluation process. This is what they had to say:

They wanted to hear perspectives from:

- Foster parents
- Adoptive parents
- Biological parents
- Service Providers
- Individuals who have FASD
- Youth

They wanted to raise these questions and guide the evaluation direction by examining the following issues:

- Physicians and talking with women
- When does the pregnancy = reality?
- Whose attitudes are being changed and in what ways?
- Each coalition may have different ideas of success for their community
- Are we having an impact?

- What enhances a coalition?
  - Participation
  - Meetings
  - Feelings of value
  - Media mentions of FASD
- What disrupts a coalition?
  - Lack of direction
  - Burnout
  - Stagnation
- Coalitions become governance of the research pillar?
- Who is our audience?
- Targeted services?
- General Services?
- Do service providers know more about FASD?
- Do individuals feel supported throughout the lifespan?
- Have communities become more involved?
- What real difference have we shown within communities?
- How are we interacting with/informing the justice system?
- What motivates men to support women?
- Messaging towards men
- Do people understand the risks around alcohol (and pregnancy) overtime
- Does the DPP feel that there has been a reduction in stigma?
- Who have we reached/educated through DPP?
- Changes in services/levels/systems → and which strategies are most effective province wide?
- Who has the power and how do we leverage it?
- Paid coalition leader → Alberta model?
  - Different structure
- Have we increased the demand for services through stigma reduction?
  - Are women coming forward?
- Can we identify indicators of stigma?
- How are resources integrated?
- How does the DPP affect the systems/budgets/resources of other sectors?
  - How is stigma embedded within the sectors?
  - Who can support financing?

A number of things regarding 'process' were raised as well:

- Should we establish an evaluation working group?

### Appendix 3



## Pruning the Future

### Research branch of the tree – this is what the leaves said:

(Note: The order of the bullets is important, as it represents the timeline that was agreed to by the group. Leaves at the top should happen sooner, leaves near the bottom will be accomplished later, as earlier leaves come to fruition).

- Do Manitobans understand the root causes of addictions?
- Research messaging that motivates partners to support women in pregnancy
- What is the power of gender in promoting dignity?
- Community strength based approach on how to create respecting and honouring and how to disseminate this (collective understanding, stories of what this means)
- How to build altruism
- Power of network, power of networking in and out and all around
- FASD Survey to target all Aboriginal communities similar to the MB FASD survey
- The questionnaire that was used, or the tool that was used, should adopt the MB FASD Centre questionnaire and make amendment and culturally appropriate
- Get firsthand experiences from those living with FASD. What has been their experience with stigma? What do they feel will be helpful or not helpful?
- Participatory Action Research approach. Funding for local projects.
- Look at existing, similar initiatives around stigma and FASD and see what has worked, what hasn't worked and learn from it
- Involve key stakeholders in research. Key stakeholders being:
  - People with FASD
  - Caregivers
  - Providers
  - Community members
  - Funders
- And hear key stakeholders stories
  - Focus group
  - One on one interviews
- Be able to measure the difference, successes, failures, struggles, from now to the future (couple years from now)
- When does pregnancy become a reality?
- How does early trauma (pre-birth and childhood) change the neurophysiology of the brain? (How much of FASD diagnoses are not due to the alcohol?)
- Building resiliency
- Increased supports in the community
- Advancing human rights

### **Popular education branch of the tree – this is what the leaves said:**

- Identifying and promoting progress that has already been made and future hopes
- Create more learning opportunities for staff people on FASD
- Mandatory minimum education for medical community, social work, etc.
- Educate and resource doctors to support alcohol friendly pregnancy
- Invite the media to our meetings
- Consider using popular media to our advantage – (Linked to common language)
- Adding “FASD Awareness” into schools (Elementary first!!!)
- Youth involvement peer support
- Health/family studies high school curriculum program- making sure this gets on the agenda in schools
- We need to educate schools on FASD (Junior/high school) – what do teachers say right now?
- Holding community gatherings with caregivers and individuals with FASD to gather information to help guide us for future services
- Collect and use stories from those with FASD and from moms to reduce othering
- Educate and empower partners to support alcohol free pregnancies
- CFS workers to have a better understanding of FASD and understand where their clients are coming from and especially to show compassion and empathy. Work closely with their clients.
- Incorporate FASD education into university degrees (BSW, RPN, PHD, specialists, etc)
- To educate front line workers on FASD
- Figure out ways that the information series is more easily accessible to general public/front line workers
- All of those that work with people suspected/confirmed FASD know about FASD generally and specifically
- Systemic networking
- Central data base of resources – MCAP website – promotion of what exists
- Balanced educational approach: spectrum of physical/brain, social issues related to FASD
- Framing the positive, to be and act positive
- Identifying resiliency
- Integration of resources
- Work with frameworks to create a video relaying our message
- Deeper knowledge on brain function – re: survey. What is FASD and how are people affected
- Media campaign – Frameworks

- Cultural teachings for our communities
- People diagnosed with FASD need specialized services for example – mental health, addictions, finances, so that stigma can be reduced
- Increased sharing ideas and strategies
- Have FASD viewed as an equal disability as others i.e.: diabetes, CP
- Continuing education (need for revisiting and repeating - people are new to jobs or forget)
- Increase Manitoba's knowledge about what it really means to live with FASD
- Practice equality and carry that teaching

### **Common language branch of the tree – this is what the leaves said:**

- Educate the media. Get them to use language to promote dignity.
- Look at systemic stigmas (such as policy, languages, existing services, etc) that have contributed to maintaining stigma
- Produce a document for doctors/nurses/social workers on common language and service provision to FASD individuals
- Media guide to reporting appropriately on FASD
- Helping physicians and other health practitioners/professionals talk with women (partner/support) about alcohol use and pregnancy
- General public education about addiction and how it contributes to this issue
- Rename FASD to reduce stigma

### **Shrub – this is what the leaves said:**

- To provide more supports while children/youth are waiting to be assessed
- To expand diagnostic capacity (adults)/shorten the waitlist period
- Educate and empower persons with FASD to aspects of positive choices, lifestyles, etc – Strengths based approach
- Decrease barriers/criteria to access to supports, funds, housing, etc. Not based on IQ but on needs.

### **Trunk – this is what the leaves said:**

- Coalition leader – leader of all coalitions – spokesperson – chair of chairs for DPP
- Target audiences – medical, education, justice, and social
- Target those with power to promote change/awareness in related fields – multisectoral
- Strategic political engagement – Re: education, health, justice systems, etc.
- Bring Subcommittees together - meeting
- Eliminate stigma by practicing that we are all equal and carry that teaching – DPP now
- Involve people who live with FASD. We need their perspectives and input.
- Meeting of all health directors and chiefs for all reserves to be able to hire a coalition director – inclusion of all 63 FN communities
- Invite more FASD programs to meetings

### **Clouds - this is what the clouds said:**

- Fewer Children born with FASD
- Information is presented in a way that maximizes engagement for all Manitobans
- Meaningful engagement techniques are identified, validated and used
- Manitoban's have an accurate understanding of FASD and use appropriate language

Appendix 4

**Map of FASD Coalitions in Manitoba**

# Map Of Manitoba Regional Health Authorities

