

UBC, Interprofessional Continuing Education's mandate is to provide advanced, up-to-date, interdisciplinary professional educational programming to health professionals, service providers, policy officials, researchers and the public on a variety of topics. The pre-conference day "Let's Talk: Stigma and Stereotypes, Where Do We Begin?" was a part of the 7th International Conference on FASD: Research, Results and Relevance – Integrating Research, Policy and Promising Practice around the World, sponsored by IPCE at UBC.

Ethics statement: The information presented in this summary comes from a workshop where participants were free to submit anonymous cards for the purpose of adding to the workshop conversation. This is not a research project but reports on the presentations and conversations, both orally and through the cards. Opinions expressed in this document do not necessarily represent the views of all participants at the event, committee members or their affiliated organizations.

PRESENTERS

Peter W Choate, Ph.D, Assistant Professor, Social Work, Mount Royal University, Calgary, AB
Jan Lutke, Conference Chair, Vancouver, BC
George F. Koob, Ph.D. Director, National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health, Bethesda, MD
Patrick Corrigan, PsyD, Distinguished Professor of Psychology, Lewis College of Human Sciences, Illinois Institute of Technology, Chicago, IL
Kathleen Tavenner Mitchell, MHS, LCADC, Vice President and International Spokesperson, National Organization on Fetal Alcohol Syndrome (NOFAS), Washington, DC
Bernadette Fuhrmann, Classroom and Community Support Worker, FASD Community Education and Support Consultant, Founder of Wheel of Life Support Services, South Slokan, BC
Niall Schofield, Adult with FASD, Public Speaker, Martensville, SK
Myles Himmelreich, FASD Consultant, Motivational Speaker, Vancouver, BC
Facilitator: Paula Stanghetta, Facilitator, Paula Stanghetta & Associates, Kitchener, ON

EDITORS

Peter W Choate
Jan Lutke
Kristina Hiemstra
Paula Stanghetta

Contact Information:

To contact Interprofessional Continuing Education or receive updates in regards to upcoming initiatives:

Email: Kristina.ipce@ubc.ca Website: www.interprofessional.ubc.ca

Mailing address: 105 – 2194 Health Sciences Mall, Vancouver, BC V6T 1Z3

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Let's Talk

Stigma and Stereotypes – Where Do We Begin?

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Introduction to the Day

Presented by: J. Lutke

The first step to getting somewhere is deciding you are not going to stay where you are. And we must move, for the world of FASD has not, to date, had any significant conversations about stigma and stereotyping. There are many reasons for that. But we can no longer afford to avoid the difficulties inherent in such painful discussions. For when you deny or ignore, you delay that which, when accepted and faced, can be conquered. We must face the unease, the fear, the isolation, the exclusion and the marginalization that our reluctance to tackle this issue has helped to deepen.

So, today, we are beginning that journey. We don't know if we are starting in the right place, but we are starting in the only place we can – here with all of you. To truly change the course of stigma we need everyone to come on this journey with us.

Change calls for commitment. And it will take all of us to ensure the work we hope to begin today commits us all – personally, professionally, organizationally, locally, nationally, internationally - to doing what we must, where we can, when we can and how we can – each of us.

None of us can truly know what it is like, to be stigmatized and stereotyped as a woman with an alcohol use disorder, or as a person with FASD; we can only think we do. So, we need to listen to – and truly hear – what experts can tell us, even if it makes us uncomfortable. We need to have open, honest dialogue that puts the issues, biases and beliefs on the table for respectful discussion from differing perspectives. We need to give permission to ourselves and to others to speak and to have patience with – and hear - viewpoints that differ from our own, for without discussion, things will never change.

We need to challenge what we think we know and what we believe. We need candor, open and honest conversation, not uncomfortable silence. We need to consider that, with the best of intentions; things have not turned out as we might want. Why?

Because in the paraphrased words of a woman named Kelly De Bie, “the stigma of alcohol use (*and as we know in pregnancy*), alcoholism and addiction (*and FASD*) can take people and swallow them whole. It can rob them of everything they value, everyone they love. It can strip them of all they care about, rob them of reason and logic. It can convince them they are not worthy, that they have failed not just themselves, but everyone else. It tells them they are broken and irreparable. Then it shoves them back down and does it again – and again – and again.” Our society says they failed because they did not try hard enough, because they are stupid or lazy or selfish; because they don't really care or they “would” – whatever “would” is. And that stigma is passed on to their children and to the other families who also love them.

This process of addressing stigma might lead us to consider the work of many people in the field of addiction, alcohol use and FASD that led us to characterize things in certain ways; ways that may be different than how we understand things today; but ways that have not changed how we – the general public – see things and believe. And we must respect the work of everyone in this field because they cared enough to do the work. But today is a chance to learn together, to change how we think and how we talk; to expand our understanding; it is a first step.

I believe this is personal to everyone in this room. Chances are, everyone in this room has been affected or knows someone who has been affected by alcohol use. I am the child of an alcoholic who died of alcoholism. I am the mother of several who struggle with alcohol.

When I thought about what I wanted to say to open this day, I came across the work of many people who said it better than I could. So, I want to capture some of their words along with my thoughts.

Jan Lutke's opening remarks were so powerful! Terrific effort on such an important topic. Many lives will be changed. The organization of the day was excellent and productive. (Judge)

In this field, each of you knows someone – clients, but also in your personal life - who is addicted to alcohol or drugs; you just may not realize it, or perhaps acknowledge it in your personal life. Or you know, but you hide their addiction because of the social stigma. Or you don't hide it, but you shame them instead. Or you don't shame them, but slowly phase them out of your life because you don't want to be around them anymore; or – importantly in this field of work - because you cannot do it anymore. Or you keep them around but talk about them behind their backs, discuss how sad it is that they “refuse” to get help; and consider yourself to be “better” than they are. Or they try to get help and sometimes they get better for a while. And then they relapse.

The trouble with addiction is that it really isn't about the drugs or the alcohol, no matter how much most people seem to believe that. Addiction is a means to an end – to try to transport oneself somewhere else, to try and feel better, if only for a minute. Most addiction is self-medication for things that people cannot cope with in real life. They just want to feel better. They want to feel normal. They just want/need to stop feeling everything else for a little while.

A man named Chuck Palahniuk, in a piece he wrote called “Choke” said, with some additional thoughts from me, “When you become an addict, you can go without feeling ANYTHING except drunk, high or hunger. Still, when you compare that to all the other feelings of sadness, loneliness, shame, guilt, anger, bitterness, fear, worry, depression, unbearable pain and utter despair.....well, an addiction no longer looks so bad. In fact, it looks like a very viable option.” Think about that. Then add to that, the experience of abuse, neglect, poverty, insecurity, violence and mental health disorders.

A man named Wendell Berry said, and I quote: “We need alcohol and drugs because we have lost each other.”

Those who turn to alcohol don't want to be alcoholics. Those who turn to alcohol don't want to lose their relationships. Those who turn to alcohol don't want to throw away their lives. Those who turn to alcohol don't want to die. Those who turn to alcohol don't want their children to grow up without parents. Those who turn to alcohol don't want to lose their children. And no woman - ever - chooses to give FASD to her children.

The problem is that our systems labour under the illusion that alcoholism and addiction are criminal issues, medical issues, social issues on the fringes that can be fixed with rehab. They ignore the fact that alcohol and drugs aren't the problem.....what led that person to drugs in the first place is the problem. Alcohol and drugs are just a means to an end. We must treat physical withdrawal, emotional withdrawal, social withdrawal, psychological withdrawal....for women, for families, however they are constructed, and for those with FASD themselves.

Until you have been there, you cannot know what it is like. Until you have been there – yourself – we do not have the right to judge, but we do – each and every one of us.

Today is the first step in beginning to change this. We are all, together, standing in a minefield full of holes from already exploded landmines that we must walk through if we are to deal with stigma. We need each other and we cannot walk through this alone. There are many landmines and as we go through the day, we are bound to step on a few we did not know were there. We *WILL* make mistakes. The presenters

WILL make mistakes. *YOU* will make mistakes. *ALL* of us will make mistakes. The question is: what will that teach us?

We need to see today as a chance to change how we think and how we talk. We are all learning together so we can begin to change how everyone acts. Remember, the first step to getting somewhere is deciding you are not going to stay where you are.

Introduction

Authors: P. Choate, J. Lutke, K. Hiemstra & P. Stanghetta

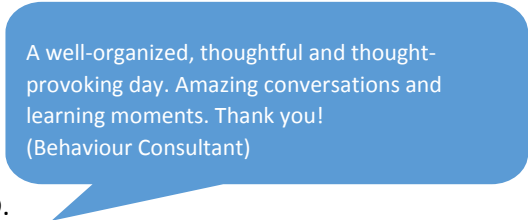
Background

Stigma often refers to negative attitudes (prejudice) and negative behaviour (discrimination) toward people. All human beings have the right to human dignity. But in the field of FASD, little effort has been made to understand the significant role that stigma and stereotyping play in how we perceive women, women with alcohol use problems, individuals with FASD and how we, as individuals, interact with and contribute to that role. Because this is such a difficult discussion, one that causes unease that we fear may cause further stigma, and that requires we look within ourselves, the field has avoided it. This has the unintended consequence of deepening the marginalization, isolation and exclusion of those most affected: women, individuals with FASD, and their families.

Purpose & Outcomes Expected

The purpose of this day was to begin a much needed dialogue about stigma among researchers, clinicians, practitioners, service providers and others working in the fields of alcohol use, addiction, women, and FASD.

By bringing in experts from the field of addiction, alcohol use, stigma and those whose lives have been most directly impacted, our hope was that participants would consider their work and that the pre-conference day might lead us to understand things differently from how we understood things before.



A well-organized, thoughtful and thought-provoking day. Amazing conversations and learning moments. Thank you!
(Behaviour Consultant)

During this session, delegates:

- Challenged their thinking around stigma and stereotypes
- Broadened their understanding of the science and roots of stigma
- Heard from those who have lived with stigma all their lives
- Engaged in discussions that can lead to the identification of potential directions for change

For a list of the Planning Committee see Appendix I

Excellent session! The lectures were wonderful. Discussion in a multidisciplinary environment was very educational in itself.
(Pediatrician)

Schedule & Presenters

This was a full day session, 8:30 am – 5:00 pm, held as a pre-conference during the 7th International Conference on FASD: Research, Results and Relevance – Integrating Research, Policy and Promising Practice around the World at Westin Bayshore, Vancouver, BC, Canada on March 1, 2017. Presentations for each topic were limited to approximately 30 minutes per topic so participants would have ample time for in depth discussion at round tables.

Welcome & Opening Remarks

Jan Lutke, *Conference Chair, Vancouver, BC, Canada*

Overview & Facilitator

Paula Stanghetta, *Facilitator, Coach, Trainer, Paula Stanghetta & Associates, Kitchener, ON, Canada*

Topic 1 | Evolutionary Origins of Stigma and the Intersectionality of FASD

Peter W. Choate, *PhD, Assistant Professor, Social Work, Mount Royal University, Calgary, AB, Canada*

Question: What is the purpose of stigma?

Topic 2 | The Neuroscience of Addiction: Is it a Choice?

George F. Koob, *PhD, Director, National Institute on Alcohol Abuse and Alcoholism, National Institutes of Health, Bethesda, MD, USA*

Question: What do we do with this information?

Topic 3 | What the Science has to Say about Changing Stigma

Patrick Corrigan, *PsyD, Distinguished Professor of Psychology, Lewis College of Human Sciences, Illinois Institute of Technology, Chicago, IL*

Question: Where do we begin to change stigma?

Topic 4 | Living Stigma - How Social Media Anonymity and the Words We Use Sustain Stigma

Kathleen Mitchell, *MHS, LCADC, National Organization on Fetal Alcohol Syndrome (NOFAS); Founder, Circle of Hope (Birth Mothers Network) and the Stamp out Stigma Program, Washington, DC, USA*

Panel Presentation: Living with Stigma – The Not So Pretty

Bernadette Fuhrmann, *Classroom and Community Support Worker, FASD Community Education and Support Consultant, Founder of Wheel of Life Support Services, South Slokan, BC, Canada*

Myles Himmelreich, *FASD Consultant, Motivational Speaker, Adult Leadership Committee*

Niall Schofield, *Adult with FASD, Public Speaker, Martensville, SK*

Question: How do we change 'all the right things' we have been doing?

Summary

Peter W. Choate, *PhD, Assistant Professor, Social Work, Mount Royal University, Calgary, AB, Canada*

Overview of the Day

450 delegates, approximately 8 individuals per table, were seated in rounds with one table facilitator at each table. Even though seating was open in the morning, most tables had individuals with very different backgrounds both in regards to professional and geographical representation (see Appendix II for attendee statistics). In the afternoon individuals were moved in order to mix up the participants even further.

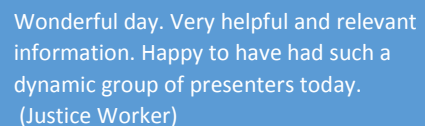
Prior to individual presentations, the day started with an initial question that delegates were asked to consider: “What is the purpose of stigma?” This question was the only one answered individually in writing and responses collected.

Then, the day was divided into four topic areas (see schedule on page 7). Each topic began with a presentation by an expert in the area, which provided key information that needed to be understood and considered in the context of the specific question and group discussion which followed each presentation. Ample time allowed for deep discussions at the tables and by the end of each discussion the table facilitator captured the responses from the table on an index card and handed this in.

The workshop facilitator, Paula Stanghetta, synthesized responses into a presentation delivered in a lunch time session on Saturday, March 4 (during the conference).

Responses from the initial question that opened the day have been included in this report in the format of a word cloud. Dr. Peter W. Choate coded the responses from table discussions and these have been summarized in this report.

Attendee Statistics in the form of breakdown of participants by role and by profession can be found in Appendix II



Wonderful day. Very helpful and relevant information. Happy to have had such a dynamic group of presenters today.
(Justice Worker)

Topic Specific Questions

One question followed each presentation.

Topic 1: What is the purpose of stigma?

Topic 2: What do we do with this information?

Topic 3: Where do we begin to change stigma?

Topic 4: How do we change ‘all the right things’ we have been doing?

Summary of responses from Pre Presentation Question

Summarized by: Peter Choate, PhD

We began the day by asking participants to individually reflect on the core question the day was framed around: ‘What is the purpose of stigma? Why?’ After allowing a short time for them to contemplate and to individually record, participants were invited to share their reflections with others at their table. The responses were varied.

Very thought provoking! Makes you reflect on your participation with stigma. Challenges you to be more mindful.
(Administrator/ Manager)

Power was one of the most prominent themes. It had many faces, however. This theme include the notion of creating differences; one being better than the other; being able to judge the other person; “hush” the conversation; separate through a “class” system; divide the communities; categorize people.

The words used were impactful – oppression, ignorance, judgment, finger pointing, shame, distance, other, avoidance, generalize, injustice, labeling, disapproval, dehumanizes, disempower, exclude, hurt, social order, scapegoat. These words all spoke of power dynamics and were prominent throughout the responses.

On the other hand, some participants saw themes in stigma that could be capitalized upon for prevention. These tended to be ways in which **prevention** might be leveraged by showing “opportunity to learn” from the damage of FASD. As one comment noted, “A way of telling people that drinking during pregnancy is not acceptable.” As another put it, “Possible as a means to shape behavior”. How this might be expanded into social policy was seen in the comment, “social function to discourage behavior that society does not desire.” Certainly, **education** was seen as the most frequent positive in the stigma conversation. “Should provide an impetus to educate others/to provide appropriate support and assistance / to help deal with addictions / to prevent further cases of FASD.”

An interesting, somewhat unique perspective came from one participant who saw stigma as a way to “**unite** different fields of experts; helping the children; getting them together.” This raised the idea that if an Interprofessional understanding could be developed around the damage of stigma, perhaps a common approach could be developed to attempt to destigmatize FASD.

The Word Cloud on the next page is a representation of the responses.

Presentations & Summary of Responses of Each Topic

Topic 1 | Evolutionary Origins of Stigma and the Intersectionality of FASD

Presented and summarized by: Peter Choate, PhD

Stigma is an active force in the lives of women with substance use disorders, people with FASD as well as their families and support systems. Stigma serves the purpose of isolating, segregating and “othering” these people. Stigma creates a perceived qualitative difference between the “average” population and four particular groups:

This presenter opened up my thoughts of the complexity and number of sources of stigma (Clinical Psychologist)

- The birth mother
- The person diagnosed with FASD
- The supports around the diagnosed person (family, friends, informal supports)
- Those working with clients with FASD.

Stigma has, as a driving force, the belief that the mother failed in her duty to protect a fetus. It presumes that the pregnancy was intentional, irresponsible and should have been avoided if the mother was not able to be sober. Stigma fails to recognize the connection between substance abuse and trauma. It fails to recognize that many of these pregnancies were unplanned and the result of sexual assault or unwanted sexual activity. It also fails to recognize that mothers do not plan to have a child with FASD.

In addition, messaging about alcohol and pregnancy can be shaming and often not connected to the social reality of high risk mothers. There are also confusing messages about whether any amount of alcohol use in pregnancy is acceptable. Examples were given in the presentation of these confusing and often contradictory messages.

Stigma also arises from catastrophizing FASD. Prevention, intervention and treatment messages often start from the most severe cases focusing on limitations and poor outcomes as opposed to possibilities and good outcomes. This leaves the public with messages of incapacity, negativity and hopelessness as the story of FASD. Perception is that nothing *can* be done so nothing *is* done.

The presentation attempted to outline an argument for changing the messages to recognize:

- The socio-economic reality of many mothers with FASD and/or at risk of having a child with FASD. This is to ensure that we are talking with these women in ways that relate to their lived reality.
- Understand the role that trauma plays as motivating and sustaining forces of substance use disorders.
- Change the language about mothers, being vigilant about avoiding “bad” mother messaging.
- Understand the complex systems that mothers must traverse in order to get supports or have hope of being involved in the life of their child.
- Alter the discourse about FASD in a way that helps the criminal justice, child protection, mental health and substance abuse systems see reasons to engage, support and sustain relationships with person diagnosed with FASD even when that may be difficult.

It was also indicated that it was time to engage with harm reduction discussions. For at least a significant portion of those with addictions, complete sobriety may be beyond capacity during the time of pregnancy. They face many pressures of which pregnancy is only one.

Professionals must attend to their own language and positioning with clients and families. They must avoid being the “good other” while the client is the “bad (or damaged) other”. Their obligation is to see the worthy person, who has capacity and opportunity and should not be part of the discourse-supporting stigma.

Summary of Responses after Topic 1: What is the purpose of stigma? Why?

Summarized by: Peter Choate, Ph. D

I love the fact today all sessions discussed focussed on stigma and how to remove it.
(Birth parent)

This question was asked a second time after the presentation by Dr. Peter Choate. While many of the same themes were expressed from the pre-presentation discussion, much more complexity arose as participants expressed different understanding. Some perspectives saw an evolutionary nature to stigma that may have served a purpose viewed as valuable, at a different point in time.

Some examples below highlight the wide range of responses:

- “Evolutionary advantage in doing so stigma solidifies hierarchy.”
- “We use stigma to help someone fit into a system... ..To educate and change behavior. To fear monger.”
- “Makes example of FASD mother so that other women will not ‘go down same route’ (or FASD mother / future pregnancies). Therefore, stigma aims to be preventative for individuals and society.”
- “Survival of the fit vs. unfit”
- “Stop an ‘unsavoury’ behavior that society doesn’t agree with ‘shame’.”
- “Step in working towards prevention.”
- “Understanding stigma is... “Opportunity to move forward – acknowledge, empathize, accept, transcend. Explore the determinants of environment that lead to disparity.”
- “Tool we use to categorize / organize something in a way that makes sense from our personal lens.”

There was also thought about the various **contexts** of stigma. For example, one participant noted, “Stigmatization is highly related to cultural context and the community from which we come.” Some contexts were seen as worrisome in that they protected the beverage alcohol industry, adds to social control and maintains the privilege of a “patriarchal society.”

Power dynamics remained the most prominent theme. The notion of control, separating, “othering”, compartmentalizing were examples of how this theme carried on from the pre-presentation themes. A new facet of stigma was seen as a form of societal “aggression” towards those with FASD. One participant offered a slightly different version of power, “Stops people from being compassionate.”

Thought was given to the position of **professionals** in the stigma discussion. “As participants in the system, we contribute to the oppression of others, not our intent.” Another twist in the perspective came from a participant stating, “Stigma is attached to funding. Creates employment. Perpetuates the class system – provides archetypes.”

Stigma creates **discourse** of differences. “Stigma can lead to overgeneralizing about groups / individuals....to compartmentalize groups.”

“To alleviate fear – if I place it on you, I don’t have to look at me.”

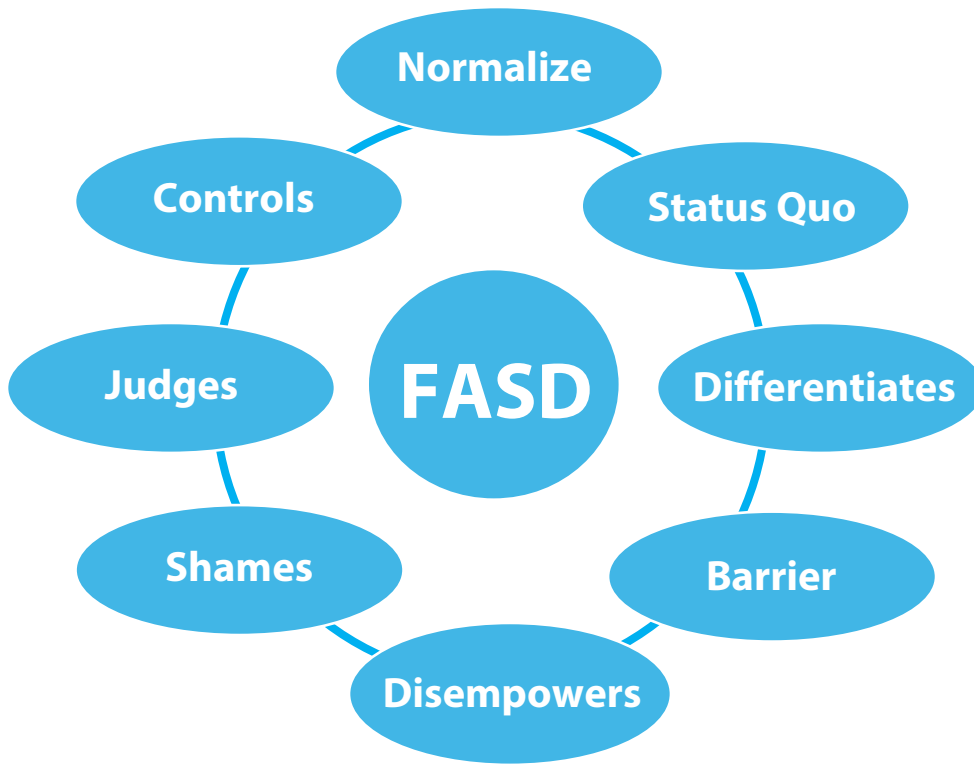


Figure 1 – Intersecting nature of stigma

Topic 2 | The Neuroscience of Addiction: is it a Choice?

Presented by and summarized by: George F. Koob, Ph. D.

Drug addiction involves a three-stage cycle—binge/intoxication, withdrawal/negative affect, and preoccupation/anticipation—that worsens over time and involves changes in brain neurocircuitry in the brain reward and stress systems. Using such a framework, the pathophysiology of addiction reflects an

This was a fantastic presentation. Clearly the presenter is an expert, but just as importantly, he could communicate his expertise to a large group of varying neurobiological knowledge. Bravo! (SLP)

increase in the incentive salience of drug-related stimuli/pathological habits in the binge/intoxication stage, reward deficits/stress surfeit activity in the withdrawal/negative affect stage, and executive function deficits in the preoccupation/anticipation stage to provide a powerful impetus for compulsive drug-seeking behavior. These domains of dysfunction correspond to allostatic neuroadaptations (non-homeostatic process of maintaining apparent motivational function stability via changes in the brain) in three key neurocircuits, respectively: basal ganglia, extended amygdala, and prefrontal cortex. Interacting with these functional changes are developmental (exposure to abuse, stress, or alcohol), genetic, and epigenetic factors that convey vulnerability to the initiation and maintenance of addiction and relapse.

The allostasis perspective opens a window on the medicalization of addiction or the concept that addiction is a brain disorder that requires treatment to return the brain's motivational systems to homeostasis. In the original conceptualization of allostasis in pathophysiology, chronic illnesses, such as hypertension, diabetes, and obesity, represented a break with homeostasis, in which the individual remains somewhat functional but at a new dangerous set point. High blood pressure is a disease, but not a choice, although choices in exercise, diet, work level, and stress all contribute to the etiology and maintenance of high blood pressure and relapse. An identical argument can be made for addiction. Such a neurobiological perspective reveals a medical condition that cannot be dismissed as a bad choice but at the same time conveys responsibility for obtaining treatment to sustain recovery as with any other medical condition.

Summary of responses from: "What do we *DO* with *THIS* information?"

Summarized by: Peter Choate, PhD

Perhaps the most prevalent theme arising out of this presentation was the value of **knowledge**, which permits differences in education, understanding, inter-professional linkages and the possibility of different interventions. Understanding the underpinnings of substance use disorders offered opportunity to break down stigma. The science was seen as powerful and led to participants exploring how the data could be used. Examples of the commentaries includes:

- "Use this information to link topics and knowledge rather than working in silos."
- "Understanding circuits can decrease stigma"
- "Tailor intervention to stage of addiction/individual options."
- "Look at issue in a broader way."

- “Have more realistic expectations of people with alcohol use disorder. Not easy to cure, chronic illness.”

The presentation opened up understanding about the **complexity** of substance use but in a way that the participants wrote of shifting opportunities from their own changes in understanding. “Realize we need to be diverse in our treatments and prevention. Realize we are more similar than different; we all want to feel safe.” Another observed the presentation required personal changing, “Make us more thoughtful and take things in account.” The link to trauma and life experience was summed up “Learn to understand it better: understanding link to trauma / abuse; colonization; see bigger picture...Addiction is a pediatric issue – drinking in adolescence is a medical issue. Addiction is not a moral issue – see it as a brain problem.”

Several participants identified the conflicting messages in society around alcohol as the “acceptable drug”. However, suggestions were made that the science in this presentation could be used for **public policy** to address drinking age, price of alcohol, marketing, access”. The challenge in this was clearly articulated, “Drinking is cultural issue”, “Facilitate a change in culture.” “Look at issue in a broader way – individuals can’t make change without support / community support.” This was noted to require actions around legal age of drinking (versus age of brain development), parenting attitudes around drinking/alcohol as well as socio-cultural issues advertising, education, treatments of marginalized populations as to the constant flow of mixed messages about the role of alcohol in society.

Related to that, participants identified the need to go further with using the data to support families, communities with messages of substance use disorders as **medical** with treatments that provide “long term support, it is not a ‘30’ day program.” In this respect, stigma was seen as “an obstacle to treatment/prevention/remediation.” One participant summed up this message noting, “De-stigmatize alcoholism as a medical problem.”

Responses also indicated a need for **further discussion** around such topics as harm reduction, pharmacological treatments and a greater diversity of treatments. As a long term brain disorder, the idea of “early and sustained supports...removing barriers for those to access treatment program...embed treatment programs in social networks.”

Participants indicating that issues of “pre-existing trauma, attachment and resiliency” were not addressed in the presentation but need inclusion in the discussion saw a **gap** in the material. Following on this, an interesting summative comment stated:

“Professional pairing is required about the science of addiction across all spheres of care – health, education, justice...This knowledge challenges social norms. Assist with decreasing stigma and decreasing blame. Facilitate trust and is needed to enable disclosure of need. Teenagers are open, a lot more than people give them credit for...open minded and hungry for information...revise information into components / style.”

Thus, there was a high receptiveness to the science with creative, and sometimes challenging ways to consider application.

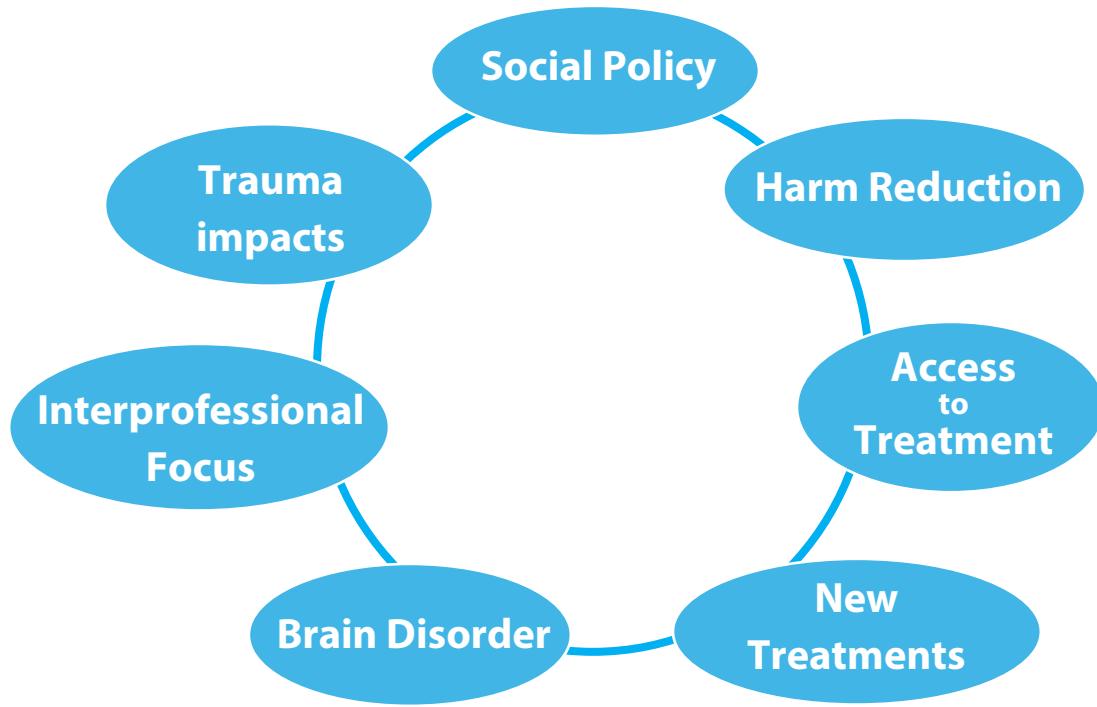


Figure 2 - Themes arising from Neuroscience of Addiction: Is it a Choice?

Topic 3 | What the Science has to Say about Changing Stigma

Presented by Patrick Corrigan. Psy.D.

Summarized by: K. Hiemstra

This presentation had two main goals in mind. The first, was to define stigma, both in the context of mental illness, and then in the context of substance use disorder. The second goal was to open the discussion on how best to erase stigma by explaining the unintended consequences in attempting to erase stigma, and the power of contact with those who are stigmatized.

This started to challenge my thinking of how information/ approaches can increase rather than decrease stigma.
(Clinical psychologist)

The presentation began by defining stigma in terms of stereotypes. Stigma hinges on two reactions to a stereotype – blame and pity. It also noted, that there are three types of stigma – Public Stigma (what the public does when they agree with stigma), Self-Stigma (internalizing a stereotype), and Label Avoidance (avoiding seeking care to avoid being labelled). The analogy was made that the stigma of mental illness, and the stigma of FASD are similar to the stigma of the LGBT+ community, in that it is an invisible difference. Unlike the stigma of mental illness however, the stigma of a person with a substance use disorder is different in three fundamental ways:

1. Discrimination is legal, for example criminal laws if individuals are using publicly or under age
2. Stigma is used to promote prevention
3. Some interventions worsen self-stigma

The discussion then moved on to the topic of beating stigma. It proposed that overcoming stigma requires that we ask a couple of basic questions: whose stigma are we addressing, and what are the goals in addressing it? The examples of the “colour-blind” movement to tackle racism from the 1960s, and “Don’t Ask, Don’t Tell” under the Clinton Government - both examples of campaigns to address stigma - are well intentioned, but ultimately project bad messages. While changing the language may seem like an easy way of dealing with stigma, the research shows it is not changing people’s perceptions.

It was suggested that there are three possible ways to deal with ending stigma: Protest, Education, and Contact. However, there are many unintended consequences that arise with both protest and education. It was also suggested that to overcome stigma we should move away from the educational method (although a basic education is necessary), and advises instead that the best route to decreasing stigma is by contact. Meeting people, hearing them talk, and hearing their stories helps others to understand it better. It was noted that the positive effect of contact on the general population is 2-3 times higher than that of education.

In conclusion, it was suggested that the path that needs to be followed for acceptance/ reduced stigma is credible and continues work through contact. For people to disclose, similar to the LGBT+ movement – “come out mad, and come out proud”.

Summary of responses from: “Where do we begin to change stigma?”

Summarized by: Peter Choate, PhD

This topic showed less of a consensus. There were a variety of ideas spanning many possible directions. If there was a more predominant thought, it would be around finding **strength** perspectives that allowed the person with FASD and the women who consumed alcohol when pregnant, to feel valued, have a valued self-identity and have a voice both regarding their care and their place in the community. From there, the ideas broadened:

- Make it easier for people to **disclose** the use or the diagnosis so that they can receive supports, have empathic and helpful responses and a voice in their care.
- For a mother, make disclosure **safe**. One participant noted, “To support this, reduce child removal and put money toward facilitating treatment, supporting families / moms (not foster). Another expanded this thought saying, “We have to make it safe for all women to come out: we have to overcome our feelings of being afraid that coming out will stigmatize them and their children; empower women to tell their stories of success.”
- **Connection** was another facet for change. In doing so, **humanizing** would take place creating opportunities for **partnerships**. “Work in partnerships with individuals with FASD and birthmoms and stop being their voice – stop talking for and start talking with – listen with intent.” “Move from othering to belonging”, was the contribution of another participant. Another noted, “this is an us issue”.
- Creating **stories of success** rather than the ongoing stories of detriment, weakness and failure. “Plan for success” was the call from a participant. This notion also can be seen in a comment, “Acknowledge the experts and strength of individuals with FASD and birthmoms and let them be the voice.”
- **Systems focus** was another frequent topic. Participants wrote of the many interfaces that people with FASD work through and the variety of messages that are delivered through those systems. “Venues: education system – safe, early; public media campaign. People: positive stories of success; public figures talking about or personal experiences; community centers. General: inclusive, openness – stories, social media, - positive campaign. Continuous opportunities for conversation. Stories of women coming through addiction.”
- **Professionals** were challenged in the notes by asking “what language do we use, our comfort level; influence colleagues; outside work influencing others.” “At the very basic level, we need to start changing with ourselves.”
- **Educating** was a topic that appeared in many ways:
 - Prevention
 - Informing
 - Changing the story
 - Partnerships

The ideas of connection and messaging were framed in many ways but very strongly across systems and groups as suggested in Figure 3



Figure 3

In the comments, we were also challenged to think about **what is said**. We were asked to think about the content of the messages and the degree to which they conveyed an understanding of disability, trauma and substance; the need for effective treatments and interventions for mothers and those with FASD as a preventative direction as opposed to relying only on education and public messaging. Part of this was to avoid the stories of “bad parents” and hopeless adults but instead stories of people surviving, building strengths, finding strength.

Although controversial, and contrary to the perspective expressed by Dr. Corrigan, some participants felt that changing the name of FASD might be helpful.

Topic 4 | Living Stigma: How Social Media Anonymity and the Words we use Sustain Stigma
Presented and Summarized by: Kathleen Tavenner Mitchell

No Woman Purposely Harms her Own Child!

Stigma has impeded progress throughout the FASD field since FASD was first recognized as a syndrome 44 years ago. If a plan to reduce the stigma is not prioritized, we may be in the same place as we are today in another 44 years. Being a birth mother to a child with FAS is like waving a flag that says “I am a terrible mother, and a horrible human being,” for the rest of your life. In January 2016, the Washington Post featured an article about my life experience as a woman that drank during several pregnancies. By day three nearly 8 million readers had viewed it. The article soon went viral and was featured on websites, newspapers, magazines, radio and television around the world. It trended on Face Book as the #6 topic for the following 2 weeks. Along with all of that media attention came comments from readers. The comments sections allowed anonymous people to post comments that were rooted in hatred, blame, stigma and ignorance.

Sifting through all of the thousands of comments from people around the world one thing became clear: we need to do more to address the stigma that surrounds FASD. Those comments informed us that there are a large number of people that believe that addiction/alcoholism is not a disease, but rather a self-inflicted act of selfishness. People are equally confused and misinformed about drinking during pregnancy and what FASD is and is not.

In response National Organization on Fetal Alcohol Syndrome (NOFAS) initiated the Stamp out Stigma Campaign. The first step was to address language and how people talk about FASD. The most widely used FASD public health messages refer to the woman or the mother as the cause of FASD. NOFAS recreated the FASD public health messages and removed all references to the mother as being the cause. NOFAS and their affiliates have pushed to have all government agencies, researchers, authors, healthcare professionals and advocates use the new FASD messages. Fortunately, the campaign has been well received and feedback agree that we should reframe our messages and do all we can to stop laying the blame of FASD onto birth mothers.

Below is an example of how revised language being promoted by NOFAS:

- Fetal alcohol spectrum disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual who was exposed to alcohol before birth. *Replacement for: Fetal alcohol spectrum disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy.*

The pre-conference day was exceptionally informative and really enjoyable...
... As well, the presentations from mothers who were in recovery were awe inspiring. I would like to consider having more foster parents attend presentations where recovering mothers speak as it would do a lot to reduce stigmatization. (Social Worker)

References:

Washington Post, 2016. Health Section

www.washingtonpost.com/national/health-science/this-mother-drank-while-pregnant-heres-what-her-daughters-like-at-43/2016/01/15/32ff5238-9a08-11e5-b499-76cbec161973_story.html

Topic 4 | Panel Presentation: Living with Stigma – The Not So Pretty

Presented by: Bernadette Fuhrmann,

"When we deny our stories, and disengage from tough emotions, they don't go away, instead, they own us, they define us." ~Brene Brown

I'm not sure when the stigma really began. Or what the stigma was even all about. All I know from my own experiences, is that it may have resulted in a lifetime of pain, sorrow, hardship, and grief. Of disappointment after disappointment. Of heartbreak after heartbreak. Of feelings of worthlessness, and unworthiness. Of a never-ending cycle of powerlessness, helplessness, oppression, victimization, and isolation.

Best and most valuable presentations are hearing about lived experiences. We need to hear more from the real experts on FASD – those who live it. I loved today – a fantastic topic – more needs doing (Teacher/ Researcher)

I believe this led to my inability to navigate the professional system in order to receive the help, support, and understanding I was desperately seeking and literally calling out for, if not through my words, but through my actions. But it is hard to call out for something, when you don't even know what that something is. And even if you did know, you would have to have a pretty loud voice to get those needs met, especially when you are about to lose your child.

When I got invited to come and speak to you about my experiences of how the stigma of being a birth-mom affected my life, I had no idea of what I would uncover. I had never really explored this area...until now. And what I discovered, as hard as it was, was the missing piece of the puzzle I had been searching for all my life. And I was shocked. I was brought to tears of how much I was actually "Living the Stigma". Living the disgrace. And how much it has become a very real part of my identity and how it has defined me.

At first it was the disgrace of being a promiscuous teenager who was an alcoholic and drug addict, and smoked cigarettes and had an eating disorder. And then it was the disgrace of being a pregnant teenager without a boyfriend. And then it was the disgrace of being a high school drop-out. And then a welfare mom. And then being poor and uneducated, and having to lie and steal to make ends meet. And then it was being naive enough to stay married to a polygamist, who sexually used and emotionally and physically abused me for 17 years. And then it was being a "bad mom" because my child did "bad" things. And then it was being a single mom living in the lower east side with three small children. And then it was having "criminals", "alcoholics, and drug addicts" as my friends. And then it was losing my son because I was too weak and unable to hold it all together on my own. I bought into it. All of it. And yet I didn't even know it. These stereotypes just became a normal part of my very existence.

I was the mom of a kid who no one wanted because they couldn't figure out what was wrong with him. Or maybe they did know, and were too afraid to ask? All they did, was take him from me, when all I asked for, was some reprieve. What I didn't know, was that I also needed support. I never had any, but then I didn't even know it existed. I was living in my own little hellish bubble. And I hated myself for it. I hated who I was. I hated the choices I was making. And I hated the never-ending cycle of doom and gloom I was living in. I felt trapped and I felt like a victim with no way out. So I kept indulging in alcohol, drugs, sex, food, loneliness, and isolation. I knew no other way of coping. I was never taught.

My voice was silenced at a very young age. And, although I was a very gifted artist and had high aspirations in this field, I was unable to follow my passion because I felt too unworthy of such an ideal. I still have trouble with it. The labels I was given from my parents really kept me down. I was the trouble- maker. The black- sheep. The difficult one. The hell-raiser. I was the disgrace of the family. And then I went on to become a whore- as my father would one day call me. And the next thing I knew, I got pregnant, and the father of my baby refused to believe it was even his. The pain was tremendous. So I went home, and kept on drinking, drugging, binging and purging.

Everyone knew something was wrong with my son, from the moment he was born. But they just couldn't figure it out. Or could they? My doctor didn't even question me about alcohol during my pregnancy, and I was too afraid to ask, because alcohol was a very stigmatized issue in my home. So I kept on drinking, because the medical books at that time, said that moderate drinking was ok. I didn't know how much moderate was.

I tried so hard to be a good mom, but it wasn't easy, when all I knew about discipline, was how to hit...and the harder, the better. And alcohol and hitting can be a very deadly mix, especially if it comes from an unstable person. It broke my heart in two. And it just made matters worse. When I handed my son over to social services for the first time when he was 5, all I wanted was a break. But they took him for 3 months, put him in a special foster home, and said he had serious problems. I really didn't want to lose him and I was scared to, so I asked for him back again and they let me have him. But with no supports in place, things got real bad again, and when I called them a second time, they came and threw a paper at me to sign, and before I knew it, he was a permanent ward of the court. He was only 6 years old. And you know, the hardest thing I ever had to do in my life, was to tell my sweet little boy, whom I loved so dearly, that he couldn't ever live with me again. The pain was tremendous.

So then, 2 years later, after regular weekend visits with him, they suddenly, and mysteriously stopped. And Social Services wouldn't tell me a thing. My voice and my life meant absolutely nothing to them. I still have yet to inquire about this, by the way...if his file even still exists. And after waiting for three long and agonizing years, and a million tears later, he finally made with contact me. He had been taken to the Children's Foundation because he kept running away from his foster home where they were abusing him. It was one of the darkest times of my life. And things just kept getting darker.

I wanted so badly to make a positive impression in my life, and my art was the only success I felt I had. But my anguish about my inability to meet my son's "mysterious" needs, left such a big scar in my life, that I couldn't focus on my dream without the use of drugs and alcohol. I loved him so much, and because of the guilt and shame I felt, I wanted so badly to make it up to him. But I couldn't, even though I tried again, and again, and again. I felt like a complete failure as a mother, and undeserving of a decent life. And then eventually I became the mother of a "criminal" and an "addict", and I lost all hope. So I continued to drink, drug, and purge my most of my food every single day. I had no supports, and I was too afraid to ask, even though it was recommended in his assessment at the youth detention center, and in his eventual FASD diagnosis.

So, as my son's life got more and more challenged with addictions, jails, institutions, homelessness, job losses, health issues, and broken promises and dreams, he was finally given a proper diagnosis. He fought it for 8 years after I finally put two and two together and encouraged him to get one. I believe it was because of the stigma attached to it, yet it was the best thing that could have happened to both him and myself. I finally felt useful, and I could put my use to work. I did everything I could to support him, and fought tooth and nail to get his needs, and others who were in the same predicament met. But my own needs were still being unmet.

It has been only 5 years since I've have walked into recovery from alcoholism, bulimia and tobacco. But I am still struggling with drugs to this very day. The most discouraging thing I have had to deal with since then is the absolute loneliness and isolation I still feel of being a birth-mom, even though I have been trying so hard to stay honest and open about it, and take responsibility. I find it very interesting, though that the stigma speaks the loudest in my efforts to educate my community and in my twelve-step, and treatment programs, where I have yet to be approached by just one birth-mom, willing to come forward and admit her use of alcohol during her pregnancy.

I am now totally convinced that there really needs to be more open talk of alcohol and pregnancy, and FASD when I am still hit hard with harsh comments such as... "people like me shouldn't have babies", "it is common sense to not drink during pregnancy", "how could you have done this to your son", and "it is important to own your responsibility." But the most disheartening of all is when comments such as "I don't

know why my biological Mom even did this to me”, and “...did she even love me?” gets published in our local community newspaper.

It still hurts to hear these comments, but what hurts even more, is to see the progression of my son’s developmental disability turn into an actual physical disability. The pain is tremendous. But yet, as I watch my own grand-daughter, who is almost sixteen now, follow in the same path as I did, I thank the heavens that I now have the knowledge and experience of my past, to help her move more gracefully, peacefully, powerfully, and deservingly into her own future. Because this is all I ever needed, wanted, and deserved for myself all along.

Presented by: Niall Schofield

Good afternoon. My name is Niall and I am 38 years old. I was formally diagnosed with FAS at the age of 24, but I had been told all my life by my family that I had it. But I was never told what it was or had it explained to me. I was just treated as dumb, lazy, unmotivated and generally a bad kid because that is what people thought and believed. I was never quite “good enough”. People were ashamed of me because I was different. I am aboriginal; I have FAS; I am adopted

But it has been the FAS that shamed me; that defined my life. I have been defined by my disabilities and differences, never by my strengths; and I never knew why I was in special classes at school, or speech therapy.

I really wondered for many years “Who am I?”; “What am I?”

You have people tell you in a hundred different ways that “you are not good enough”. Good enough for what? Good enough for who?

In my life I have experienced sexual abuse, rejection, addiction, attempted suicide, emotional damage, psychological scarring. I have experienced homelessness, inability to maintain relationships, loss of trust, and lost a sense of belonging

Who am I?

I have lived with fear, doubt, self-loathing, hatred, lies, running away - from what? I feel a deep shame, a deep anxiety, a deep frustration; I feel the implied judgement of others; I shut down right away or I run. I was never good enough. I bought into the stereotype and the stigma; that I would never amount to anything; that FASD was more-or-less a death sentence.

Who am I?

I was always told “you can’t”; never “you can”. I am still introduced by family to people as the “brother with FAS – that means he has brain damage”. Why? Because if I mess up, then it does not reflect on them.

Stigma, stereotypes, that’s all anyone thinks about FASD. You don’t belong; you don’t fit in; you can’t, you don’t, you won’t - never any support at all.

Yes, I am forgetful, and I forget right in the middle of things sometimes. I cannot complete many things I start; too much language is very difficult for me to process and understand; my reading comprehension is only Grade 3; I have problems with attention; I had a speech disorder; I failed in school and could not keep up by grade 6, I was a behaviour problem and I dropped out in grade 10; I cannot manage money and it is hard to keep my life together sometimes. All things I have read about FASD – but that’s not me. I fight against it – the hurt, the anxiety, the enormous self-doubt; the voice in my head that tells me I am useless

I am so much more than just this.

I have had at least 12-15 jobs in my life, when I was able to work; but always I would get into trouble or management would get upset and I would get that feeling again and know it “was time to change”.

Who am I?

I never wanted this. Where would I be today if people had believed I could do something? Where would I be if the stigma and stereotypes about FASD were not so common; so awful and determine how people act towards you?

Even now, when I tell some people I have FAS, they deny it – why? Because it is so stigmatized and if they accept that I actually do have it, then it means I am a hopeless case and I will screw up and they need to avoid me.

Denial changes nothing; it just feeds the stereotype. How am I supposed to believe in myself when no one else wants to? How is this fair or right? If you do not have help, then how you cope with FASD is the way I coped and you just believe what they say and where does that leave you? With a deep down feeling of worthlessness. Worthless equals no self-esteem; worthless equals having no value to society. Where would I be if I had had the understanding and support I needed to be a success? To avoid the pitfalls?

I want to feel success and I want to feel it as the normal part of me. I am very aware of my limitations. I live mostly day-to-day and life can be pretty scary. I am always afraid of failing. I don't want that. But what's the point? If according to society, you don't mean anything when your best efforts are not even recognized, never mind acknowledged.

I don't want to live my life in fear and doubt. I want to believe in myself, I need to believe in myself – I must believe in myself because no one else has - and this is a step on that journey. There is something deep inside of me that I have finally discovered that will not allow me to quit or to give up. When I think about what I have been through, even I am surprised I'm still here

So, who am I?

I am a man who has fought many hard battles. I am a man who has strengths. I am a man who wants to dream. I am a man who wants to achieve. I am a man who wants to look in the mirror and love himself for who he is, not hate himself for who he is not. My name is Niall and I am a man with FAS.

In closing, I want to ask you, the people in this room, to ask yourself what you, each and everyone one of you, can personally do to deal with stigma and change the future for every person out there with FASD.

We need it. We have earned it. We deserve it. And we are worth it.

Presented by: Myles Himmelreich

Years ago, terms like retarded, special needs and mentally handicapped were just words. It was society that attached stigma to them and made them sound and appear negative.

Hello, my name is Myles and I am mentally retarded, I have FAS and I am handicapped. The more you push away from such terms, the more you push away from people like me because there will ALWAYS be words.

Can you see that; do you see me?

People hope one day to work their way out of this field and get to a point where there is no FASD. What if we never get to that point? What if there will always be FASD? My parents were told I had FAE when I was a small child. It was not until I was about 35 that I was finally seen and formally diagnosed with full FAS in Alberta

Nobody can understand or see how hard I try every day to fit into society's view of what is acceptable. You can't see the effort I put in, the constant self-talk and self-control I have to use almost every minute of every day to be seen and come across as "normal" - to fit into society. I have to "act appropriately" every minute of every day. It is so tiring, so draining, having to work harder than everyone just to be seen and come across as "normal"

Do you see that now? Do you see ME?

My whole life I have known I was different; I felt disconnected from this world; that people didn't want me. What mis-directed my life for so many years was the belief that I was not good enough – period.

Such important and deep comments. Terrific capstone to the day that will not be forgotten. (Judge)

Starting at a young age, I started to question and doubt myself. The voices in my head would echo the things said around me; I told myself daily, I can't, I won't. I have told myself this in so many different ways, on so many different days for SO many years. I didn't finish school, every time I lost a job, never had a healthy relationship (always drinking and drugs); couch surfing and being homeless; that was my life. And I never understood "why"?

The problem is the way society looks at me. The problem is the way society thinks about me. The problem is the way the world has made me look at myself

We tell children "don't pick on, don't bully those who are different. We tell adults "don't judge" but they do. Well, you are picking on, bullying and judging me. Stigma and stereotyping is just the worst kind of bullying because it destroys us

Do you see that; do you see ME?

I have FAS so there are things I struggle with and things I will have to do differently. There are things I will not ever be able to do.

But I am not broken and I do not need fixing. I am learning to be okay with what I cannot do – why can't you?

WHAT do you see? Do you see ME? My girlfriend shared with me how she experiences judgement and stigma from those around her when she shares that she is dating me; dating a man with FAS. "You shouldn't date him; life will be harder; people with FAS are: always angry, have short fuses, self-medicate; never amount to anything. Is that what you see?

I try to focus on my strengths, break down barriers and challenge myself to grow. I am a motivational speaker and consultant on living with FASD. But people have seen me succeeding and, unfortunately, now my success has become another negative that works against me. People have questioned my friends in

the field and told them I could not have FASD as I am doing too well and am too successful. Why shouldn't I be able to be a public speaker? The stereotyping and stigma is right there, in front of you

Do you see it now? Do you see ME?

Even now, with healthy relationships in my life, those close to me feel the stereotypes and stigmas of FASD. My girlfriend worries about the judgements and things that people have said to her. She wonders why, when talking about me, she cannot simply say "He has FAS"; why she needs to follow it up with a list of strengths to prove I am not a loser, therefore she is not a loser for being with me. Stigma by association. Why is it "wrong" to have a partner with FAS?

Do you see it that way? Do you see ME?

I want you to understand and differentiate between the stereotypes of FASD and what the actual explanations are for what you see. If we make blanket statements and wrongly judge people with FASD AS A WHOLE we are doing the exact same thing we are trying to stop kids in school from doing – bullying.

How can I value myself if you do not?

A wise man who moonwalked and wore a sparkly glove, once said if you want to make the world a better place take a look at yourself and make the change. I'm starting with the man in the mirror and asking him to change his ways. I cannot ask society to stop stigmatizing and stereotyping me until I ask it of myself. When I tell people I have FAS they say things like "Oh, that's too bad". I've had people actually physically distance themselves from me as if it's something you can catch. Society has been distancing itself from my mother and me for years because of the stigma. Your mother made bad choices; you have a bad disability – bad meaning shameful.

Thank you for your vulnerability and challenging my own stigma (OT)

FASD is the only disability that still has so much negatively attached to it, so MUCH stigma. That is because of society's lack of understanding. Because of that, you left me and my Mom alone, with no support and to fend on our own.

Do you see that? Do you see US?

Please stop with this "us" and "them". A birth mom, an adoptive mom, a woman caring for her child is a MOM. Will you see it that way? An intelligent child, a talented child, a child with a disability is a CHILD. When will you see it that way?

My name is Myles Himmelreich and I am 39 years old and I have FAS

Do you see me now?

Summary incl. Responses from: “How do we change ‘all the right things’ we have been doing?”
Presented and Summarized by: Peter W Choate, Ph.D.

In some respects, this last question brought together ideas that were common in responses to other questions.

The discussions were ILLUMINATING, and I met remarkable people at them!
(Psychologist)

The main messages in this response set focused on changing the language and the image of FASD. This was accompanied with ideas of acceptance, “Stop trying to fix – support, empower, discover strengths, redefine what you think is success, create attainable individual client centered support plans that bring together the entire support team (cooperative and collaborative). Change your expectations to realistic ones. Meet people where they are at – celebrate success.” Changing language seemed to matter such as no longer using terms such as “external brain”.

Other suggestions included:

- Reflect on our individual role in sustaining stigma; asking ourselves as individuals how are we presenting FASD and the lived experience; are we enhancing or minimizing stigma?
- Individually consider what each one of us can do in overcoming stigma; in what way can each of us engage and contribute to changing the story of stigma?
- Move problematic substance use from a moral to a medical issue

In more subtle ways (and not necessarily from any one topic) there was an undertone of looking at the place of alcohol in society. This meant looking at the context of consumption and usage.

FASD is a disorder that has been the subject of discourses connected to stigma. There is the shaming that goes with having a child exposed to alcohol during pregnancy – it is the shameful mother. Then there is shame of having the disorder as it is related to a legacy of hopelessness where you cannot even control yourself so caregivers must be your “external” brain. This is a discourse that serves to separate and isolate. It diminishes the worth of those at risk of having a child with FASD as well as those who have FASD.

It is these barriers that stop people from seeking treatment at the time of pregnancy or after the child is born. It is also the legacy which causes child protection, health, mental health, education, and criminal justice systems to intervene from positions of there being inherent weakness that cannot be improved. It is a systemic position where disempowerment is standard.

Change is needed. The person with FASD must be seen as whole person with possibilities, strengths and hopes along with challenges. The mothers, who are often traumatized and suffering from substance abuse and mental health issues, must be seen as in need of support and understanding. The notion that she is immediately an incapable parent fails to understand the capacity of people to change and the needs of children to be connected to their families. The diagnosis of FASD does not inherently determine the worth of people; the child is not inherently incapable and the mother is not inherently shameful.

We must also be wary of assumptions that the risk of a child exposed exists only with certain groups of mothers. For example, one of our higher risk groups are young women, with no intention of pregnancy, who are binge drinking and unknowingly become pregnant.

Women are faced with conflicting messages. Society has not been clear with the determination of whether any alcohol in pregnancy is acceptable. In the presentation, several conflicting messages were illustrated. Equally, we must recognize FASD is not a racially based or a socio-economic disorder. Too often, FASD has been connected to the Indigenous peoples of Canada. It is vital to recognize that colonization and residential schools have created a vulnerability to trauma based outcomes of which FASD is one. But to say that the Indigenous peoples are predominant owners of the FASD issue is, in itself, colonial and racist. FASD is a risk that exists in our society!

When a mother goes for services for herself and/or her child, she is typically faced with a complex myriad of systems to navigate that are difficult to understand even for those professionals working within systems. We make getting help very difficult. The mother must intersect a vast array of services, often segregated or not well inter-connected, in order to get help for the complex realities that many mothers are asked to manage. Such poorly interwoven systems and services are barriers for mothers.

So too are the public policy approaches that seek to immediately remove a child from a mother due to alcohol use in pregnancy. Even worse, are policies that suggest such a mother should be criminally charged and incarcerated. Such policies serve not to effect change but rather to drive mothers further away. Such policies enhance harm not promote change.

Hope lies in enhanced opportunities to engage with families, and yes also fathers, in a way that values people, sees possibility, and integrates systems to promote well being and support.

Throughout the day we heard very diverse opinions about the impact of stigma and possible solutions; there is not yet a consensus about what should be done, but the day brought intense conversations that need to be advanced.

Closing Remarks

Presented by: Jan Lutke

I began this day by saying “The first step in getting somewhere is deciding you are not going to stay where you are”. Today we have begun a process to which we must all commit – commit our thoughts, commit our words, commit our actions, commit our resources and commit our time.

Winston Churchill said “We may not be at the beginning of the end, but we are at the end of the beginning” - *IF* and *ONLY IF* we maintain and build on the momentum begun today. We must be the change we want to see, for if we are not part of the solution, then we are – still – part of the problem, because the future direction of stigma in FASD does not exist in anyone else’s hands. It is determined by me. It is determined by you. It is determined by each of us, here, now, today.



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105-2194 Health Sciences Mall
Vancouver, BC, Canada
V6T 1Z3



+1 (604) 827-3112
kristina.ipce@ubc.ca
www.interprofessional.ubc.ca

APPENDIX I

Planning Committee

Jan Lutke, Conference Chair, Vancouver, BC

Peter W. Choate, Ph.D., Assistant Professor, Social Work, Mount Royal University, Calgary, AB

Kristina Hiemstra, B.Soc.Sc., Director, Interprofessional Continuing Education, UBC, Vancouver, BC

Paula Stanghetta, Facilitator, Coach, Trainer, Paula Stanghetta & Associates, Kitchener, ON

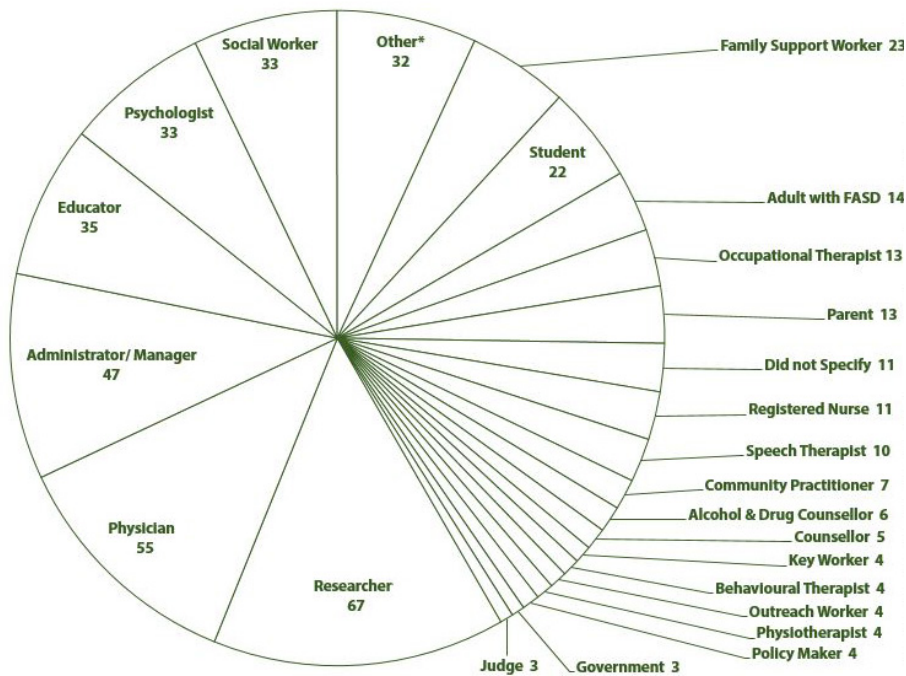
This committee worked closely with other committees for the 7th International Conference on FASD: Research, Results and Relevance – Integrating Research, Policy and Promising Practice around the World (Expert Planning, FASD Leadership, Expert Advisory and the Local Planning Committee).

APPENDIX II

Attendee Statistics

Breakdown of Participants by Role.

Over 60 roles were represented at the pre-conference, demonstrating the importance of providing a space for delegates to make connections across professions. Major professional groups included Researchers, Physicians, Administrators and Managers and many allied health professionals. In addition over 25 participants were Adults with FASD or attended with their primary affiliation as a family member.



*Others Include: Communicator, Community Liaison Worker, Community Services, Community Support Worker, Conference Chair, Consultant, Diagnostic Team Leader, Direct Care, Disability Advisor, Employment Counsellor, Evaluation Consultant, Facilitator, FASD Specialist, Foster Care Resources Supervisor, Guardianship and Trust Officer, Health Coordinator, Infant Development Consultant, Justice Program, Knowledge Broker, Law Enforcement Officer, Lobbyist, Mental Health Coordinator, Mentor, Neuropsychologist, Non-governmental Organization, Nurse Practitioner, Ophthalmologist, Orthoptist, Pregnancy Support Worker, Writer, Certified Professional Recovery Coach

Breakdown of Participants by Geographic Location

Over 450 participants attended the pre-conference day on Stigma. The majority came from Canada (65%). About 80 participants came from 30 different states in the US and the remaining 81 delegates travelled from 16 different countries. The charts below includes a breakdown of attendees by geographical location.

