

FASD

Justice and Reconciliation: Tough Questions, New Collaborations

**National Symposium
February 22-23, 2017
Final Report**

*“Achieving reconciliation
is like climbing a mountain —
we must proceed a step at a time.”*

Justice Sinclair

A Word About This Event

FASD, Justice and Reconciliation: Tough Questions, New Collaborations was informed by ongoing research from Canada FASD Research Network—specifically research in the area of FASD and justice. It is also an extension of Canada FASD Research Network’s commitment to engaging in the Truth and Reconciliation Commission’s (TRC) Calls to Action. The following provides a short overview of research and events that led to the Symposium theme.

The 94 TRC Calls to Action were released in June 2015 and called on all Canadians and agencies to undertake the work of reconciliation, addressing the historic and ongoing impact of the Indian Residential Schools in Canada. FASD was listed in two of the Calls to Action (see facing page).

Later that same year, Dr. Stewart’s research team released a national Environmental Scan of diagnostic capacity and justice programs. Following the release of the Scan, Dr. Stewart’s team undertook a cross-Canada research trip meeting with individuals, families, and agencies across Canada to better understand overall capacity to support individuals and families as well as the capacity to keep individuals in the community and out of custody.

During this trip, stories were shared about social isolation, pain, resilience, and perseverance. FASD presents individuals, families, and communities with many challenges, not least of which is the many ways that it is

misunderstood. Two of the more challenging misunderstandings, and ones that are not easily spoken about, involve racialization and trauma. There is often a misperception that FASD is “an Aboriginal problem.” This misconception is widespread and deeply troubling. The prevalence of this misunderstanding coupled with a lack of dialogue about how to engage with the TRC Calls to Action and the role of trauma as it relates to FASD, served as the basis for the Symposium.

The two-day event was meant to create a collaborative space to explore the racialized misconceptions that can surround FASD—informed by the lived experiences of mothers and families—while also creating a space to discuss trauma and paths forward as we undertake the collective work of reconciliation. We thank the wonderful speakers and participants that joined in this discussion.

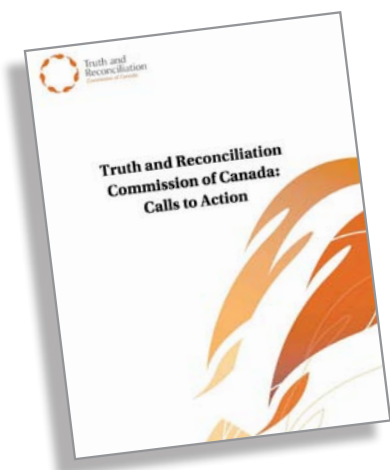
Reconciliation is ongoing and active work—it demands that we ask tough questions and seek out new collaborations to move forward.



Photo credit: Michael Bell, Regina Leader Post

The following is an excerpt from the
94 Calls to Action released by the
Truth and Reconciliation Commission of Canada in 2015.

33. We call upon the federal, provincial, and territorial governments to recognize as a high priority the need to address and prevent Fetal Alcohol Spectrum Disorder (FASD), and to develop, in collaboration with Aboriginal people, FASD preventive programs that can be delivered in a culturally appropriate manner.
34. We call upon the governments of Canada, the provinces, and territories to undertake reforms to the criminal justice system to better address the needs of offenders with Fetal Alcohol Spectrum Disorder (FASD), including:
 - i. Providing increased community resources and powers for courts to ensure that FASD is properly diagnosed, and that appropriate community supports are in place for those with FASD.
 - ii. Enacting statutory exemptions from mandatory minimum sentences of imprisonment for offenders affected by FASD.
 - iii. Providing community, correctional, and parole resources to maximize the ability of people with FASD to live in the community.
 - iv. Adopting appropriate evaluation mechanisms to measure the effectiveness of such programs and ensure community safety.



To access the full 94 Calls to Action
and the full report, please visit:

<http://www.trc.ca/websites/trcinstitution/index.php?p=890>

Executive Summary

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe a spectrum of physical, neurological, cognitive, socio-emotional, and behavioural impairments that may result from prenatal exposure to alcohol. In addition to these impairments, secondary challenges (such as involvement with the criminal justice system) may be experienced in the absence of appropriate supports and services. FASD is often discussed in the context of the criminal justice system, as individuals with FASD are understood to be overrepresented in the justice system.

In 2015, the Truth and Reconciliation Commission of Canada released 94 Calls to Action, directed at various levels of government and to all Canadians. TRC Calls to Action 33 and 34 specifically address FASD. The Calls to Action provided an opportunity to bring together policy makers, front-line workers, parents/caregivers, and students to discuss how the

TRC can be considered in justice practices. The Symposium took a holistic look at how justice programs at the local and national level may incorporate culturally-appropriate programming. This included discussions on how individuals and families can be best supported in the community and, when necessary, in the justice system.

Moreover, the Symposium drew attention to the need for programs that are attentive to the broader contexts that impact Indigenous peoples with FASD, particularly when in contact with the justice system. Indigenous voices and programs were at the centre of the discussion. Justice programs that have solidly incorporated Indigenous perspectives were also explored—from smaller community-based projects to larger programs embedded in province-wide judicial initiatives. The goal was for participants to be exposed to programs from across Canada, to gain a broader understanding



of the complexity of issues when discussing FASD in the justice system and to be introduced to new tools and networks to respond to the TRC Calls to Action.

The Symposium featured six presenters who led an exploration of how justice system programming supports people with FASD, focusing on the experiences of Indigenous individuals. This included the perspectives of parents, front-line community workers, and diagnosticians. Participants engaged in discussions focused on current practices, future directions, and the path forward. From the feedback collected throughout the event, Dr. Stewart's research team has produced 6 key findings and 18 recommendations for moving forward.

Key Findings and Recommendations

1

Culturally and Historically-Informed Practices

Participants noted that there is often a lack of culturally and historically-informed programming for individuals with FASD across systems.

Recommendation 1: Develop relationships between agencies and Indigenous communities.

Recommendation 2: Develop training focused on the TRC and the history of residential schools and colonialism in Canada for agencies.

Recommendation 3: Explore the potential for culturally and historically-informed practices within the health system.

2

Trauma

Participants recognized the role of trauma in the lived-experience of individuals with FASD, particularly in relation to the potential for re-traumatization within the justice system.

Recommendation 4: Develop and distribute training on trauma-informed practices.

Recommendation 5: Establish the capacity for trauma to be incorporated as a mitigating factor in sentencing.

Recommendation 6: Develop outreach and training material for frontline health professionals about practices surrounding diagnosis and care.

3

Advocacy

Participants discussed the ways in which individuals with FASD, families, and support agencies can advocate for greater awareness of FASD and confront the stigma surrounding FASD.

Recommendation 7: Facilitate collaborative spaces that are inclusive and welcoming of candid discussions.

Recommendation 8: Create spaces for individuals with FASD and caregivers to engage directly with policy-makers and program managers.

Recommendation 9: Facilitate spaces for individuals with FASD and families to access training.

Recommendation 10: Implement and integrate changes to programs and practices that honour Indigenous perspectives.

Recommendation 11: Establish keeping families together as a top priority informed by Indigenous perspectives.

4

Resources

Participants expressed that, while some jurisdictions have demonstrated success in establishing supports for individuals with FASD and their families, there are substantial gaps in services particularly in rural or remote communities.

Recommendation 12: Identify wise practices that best support individuals with FASD across the lifespan informed by Indigenous perspectives.

Recommendation 13: Prioritize community driven requests for supports and services with an emphasis on sustained funding.

Recommendation 14: Fund culturally appropriate diagnoses, mentorship, and respite for families, life-skills and mentoring for individuals, and ongoing support that changes across the lifespan.

5

Interagency Collaboration

Participants noted that a primary challenge to the provision of appropriate supports and services to individuals with FASD is the “silo effect” (agencies working in isolation) which prohibits effective collaboration.

Recommendation 15: Facilitate regular opportunities for interdisciplinary teams to come together to share resources.

Recommendation 16: Strike working groups comprised of federal, provincial/territorial stakeholders, and policy-makers in collaboration with Indigenous communities to implement TRC Calls 33 and 34.

6

Challenging Systems and Policy

Participants noted many barriers to individuals with FASD accessing services, including the need for maternal confirmation and justice-specific concerns (such as conditions of release and use of legal jargon).

Recommendation 17: Complete a program and policy review through a TRC lens to make appropriate modifications to programs, practices, and protocols.

Recommendation 18: Undertake a review of culturally modified/culturally appropriate diagnostic practices to modify or enhance current diagnostic practices.

Background Information

In 2015, the Truth and Reconciliation Commission (TRC) of Canada released 94 Calls to Action. The TRC Calls to Action were directed at various levels of government but also, more broadly, to all Canadians. The TRC was a result of the Indian Residential School Settlement Agreement. The federally-appointed Commissioners undertook a six-year investigation that involved upwards of 6,000 witnesses and investigated the impacts of the Indian Residential School program. The last school closed in Saskatchewan in 1996. However the impact of the Residential Schools—including sexual, physical, and emotional abuse — impacted those that attended, their families, and future generations (Truth and Reconciliation Commission of Canada, 2015):

But, shaming and pointing out wrongdoings were not the purpose of the Commission's mandate. Ultimately, the Commission's focus on truth determination was intended to lay the foundation for the important question of reconciliation. Now that we know about the residential schools and their legacy, what do we do about it? (Truth and Reconciliation Commission of Canada, 2015: vi)

Since the release of the TRC report and Calls to Action, there is now the call to move from truth to reconciliation. In an effort to move toward operationalizing the Calls to Action, the Symposium sought to carefully analyze the TRC Calls to Action focused on FASD. While FASD as a condition is not exclusive to Indigenous peoples, the fact that there are specific Calls to Action in the TRC regarding FASD indicates the need to explore how FASD impacts Indigenous

peoples. TRC Calls to Action 33 and 34 specifically address FASD and justice, and these Calls to Action provided Dr. Stewart's research team with an opportunity to bring together policy makers, front-line workers, and students to discuss how the TRC can be considered in current justice practices.

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe “a broader spectrum of presentations and disabilities resulting from alcohol exposure in utero” (Cook et al., 2016). Prevalence estimates for FASD in the general population range from 1 to 5% (May et al., 2009; Stade et al., 2009). It is estimated that FASD affects almost 400,000 Canadians (Cook et al., 2016). Currently, diagnosis of FASD is dependent on maternal self-disclosure of prenatal alcohol exposure, clinical presentation of three sentinel facial features, and presence of central nervous system impairment in at least three domains (Cook et al., 2016). The presentation of FASD may intersect with concurrent disorders, thus making reliable and consistent diagnosis difficult. Clinicians along with the Canada Fetal Alcohol Spectrum Disorder Research Network aimed to revise the 2005 diagnostic guidelines to “improve outcomes for affected individuals and families, and to inform pre-pregnancy counseling to prevent future cases” (Cook et al., 2016).

FASD, as a lifelong condition, is often examined within the context of adverse outcomes. The adverse outcomes that may be experienced by individuals with FASD are often considered to occur in relation to the primary deficits in neurocognitive functioning which result from prenatal exposure to alcohol. These

challenges may include impairments in memory, attention, executive functioning, language, and social-emotional and behavioural functioning (Mattson, Crocker & Nguyen, 2011; Olson et al., 1998; Mattson & Riley, 1998). Adverse outcomes, or secondary challenges, associated with FASD include higher rates of mental illness, difficulties in school, becoming unemployed, homelessness, and substance abuse issues (Popova et al., 2011). Additionally, individuals with FASD are more likely to have negative contact with the criminal justice system (Streissguth et al., 2004). It is important to note, however, that these challenges are not unique to individuals with FASD (Popova, 2011). These characteristics are not inherent to the primary physical disability of FASD, but rather are outcomes more likely to be experienced by any individual who lacks appropriate interventions and supports (Popova, 2011).

Researchers have endeavored to determine the prevalence of FASD within correctional and justice settings (Streissguth et al., 1996; Fast, Conry & Looock, 1999; Rojas & Gretton, 2007; Popova et al., 2011; Hughes et al., 2016). The most cited prevalence estimates suggest that somewhere in the range of 10 to 23% of individuals in correctional populations have FASD (Fast et al., 1999; MacPherson et al., 2011). In the Canadian context, there have been efforts to address the overrepresentation of individuals with FASD in justice settings.

The most recent attempt, Bill C-235, sought to amend the *Criminal Code* and the *Corrections and Conditional Release Act* to allow for consideration of FASD as a mitigating factor. Although this bill was ultimately defeated in the House of Commons, the bill along with two prior bills signals a recognition among Canadian policy-makers that the cited overrepresentation of individuals with FASD in justice settings requires attention and action.

Prior to the release of the TRC, researchers argued for culturally-sensitive approaches to delivery of FASD prevention and intervention programs (Elliot et al., 2012; Salmon, 2011; Salmon & Clarren, 2011). Concurrently, researchers also noted that the delivery of an FASD diagnosis is challenging and must be undertaken with compassion (Badry & Choate, 2015) as it can be seen as a diagnosis for both mother and child in which the mother is vulnerable in many ways (Berube, 2011). Part of the vulnerability comes from the stigma associated to the disability (Bell et al., 2015) but also the racialization that compounds the stigma (Oldani, 2009; Stewart, 2016). One mechanism to combat the racialization and stigma is to listen and take direction from Indigenous mothers and families when designing prevention and intervention programs (Stewart et al., 2017). Decolonizing research, training, and practices are central to the work of reconciliation.

Event Summary

FASD Justice and Reconciliation: Tough Questions, New Collaborations

University of Regina
Host: Dr. Michelle Stewart
February 22-23, 2017

The Symposium was held on Treaty Four Territory and included various participants who came together to discuss challenges and next steps for interagency collaboration, challenging policy and systems, resources, culturally safe approaches, addressing trauma, and demonstrating advocacy.

FASD: Tackling Stigma in Daily Life

Ramada Inn, Regina
Host: Dr. Michelle Stewart
February 22, 2017 (7:00-8:30 pm)

Symposium attendees, family members, and community members discussed the stigma surrounding FASD. Discussion focused on lack of access to services in addition to prevention messaging which, at times, seems to be insensitive to individuals with FASD and their families. Mothers and family members shared their experiences with and reactions to prevention messaging, which led to discussion on how stigma can be challenged through sensitive prevention messaging.

Participants

Sixty participants from across Canada attended the Symposium hosted at the University of Regina. The event included individuals from the ministries of justice, health, and social services. Also in attendance were researchers, policy-makers, mothers, and various representatives from community organizations.

Presenters

Knowledge Keeper Noel Starblanket started the event and was then joined by University of Regina President Vianne Timmins who offered an opening address. Dr. Stewart briefly discussed her research and provided an overview of the event. Speakers at the Symposium reflected a variety of practices and research in regard to FASD with a balance of justice, community, health, cultural, and diagnostic backgrounds. Presenters were dispersed among three roundtable discussions throughout the event.

Roundtable One: Holistic and Culturally-Safe(r) Approaches to Programs and Practices

Lisa Lawley, Kermode Friendship Center,
British Columbia

Rachel Tambour, Tree of Peace Friendship
Centre, Northwest Territories

**Roundtable Two:
Taking up the Challenge:
Legal and Ethical Considerations**

Laura Hoversland, Justice Manager for Council of Yukon First Nations, Yukon Territory

Samaya Jardey, Through an Aboriginal Lens, British Columbia

**Roundtable Three:
Bridging by Fostering
Culturally-Safe Collaborations**

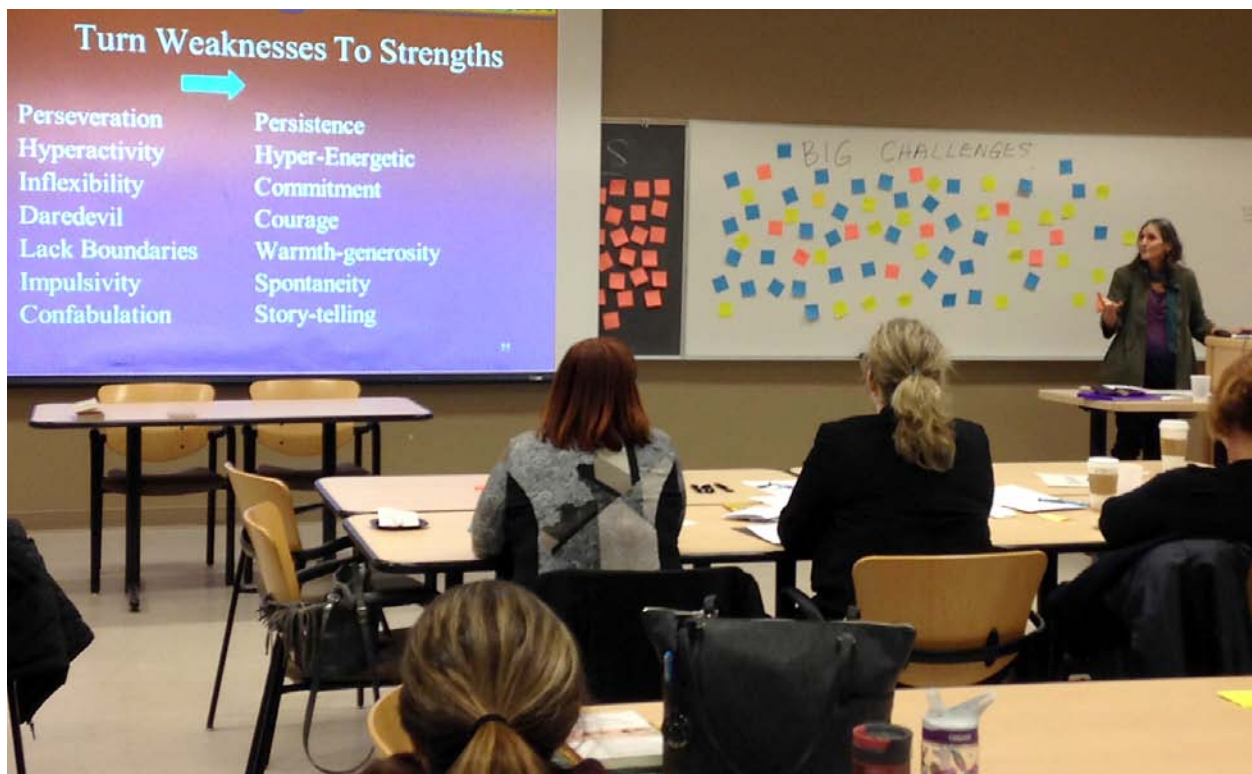
Lisa Workman, Four Directions Community Health Centre, Saskatchewan

Dr. Lori Cox, Eastern Door Diagnostic Team, New Brunswick

**Summary of Table Top
and Guided Discussion**

Following welcomes and introductions, participants were asked to “map the issues” by responding to questions, including: (1) Where are we now?; (2) Where do we want to go?; and (3) What is needed to get there? This initial discussion allowed for participants to reflect on the current position and dialogue surrounding FASD, and discuss ways in which they can move forward within their own jurisdictions.

Participants engaged in discussion to identify the major themes from the event, to facilitate new strategies, and to develop next steps for reconciliation. Participants divided themselves between three main areas to come up with one working strategy moving forward from this event. The groups focused on: (1) Prevention Messaging; (2) Justice; and (3) Culturally Appropriate Practices.



Participant Feedback

During the event, organizers distributed three separate evaluation surveys to participants: a pre-event survey, an evaluation at the end of day one, and an evaluation at the end of day two (see Appendix 3). These surveys sought to collect information about participant backgrounds, and to assess the overall utility and applicability of the presentations, and discussions.

Participants reported that the presentations were valuable in expanding their knowledge of the challenges surrounding FASD and reconciliation.

Really appreciated the personal experience sharing that both Lisa and Rachel gave to the group. Greatly enhances understanding and gives context to barriers and obstacles that exist!

Participants also reported that the opportunity to engage and collaborate with participants from other jurisdictions was particularly valuable, and these connections should continue to be fostered beyond the conclusion of the Symposium.

The group discussions were very valuable—I am learning a lot about programs in other jurisdictions and ideas around improvement.

Great networking—interesting opportunity to learn about programming in other provinces in Canada.

All of the participants were very engaged in the discussions. There was a good balance between presentations and time to discuss ideas.

Overall, participants reported that the sharing of additional perspectives and a safe space to collaborate would positively influence their

future work specific to FASD, justice, and reconciliation.

Felt it was a really safe and supported environment, allowed everyone to share thoughts and perspectives.

Great conference, resources, informative discussions, and will continue to affect positive change.

Learned much. Open, respectful dialogue.

I will take these issues into account when discussing/developing justice policies.

Will make efforts to change policy and implement training in area.

Sharing programs and challenges, sparked lots of ideas in how to move forward.

Summary of Participant Feedback

Participant feedback was overwhelmingly positive. Presentations were considered valuable in expanding specific knowledge bases on FASD and associated challenges. As conversations about FASD continue to develop over time, we can see a move from conversations about what FASD is, to what we can do to better address this disorder, demonstrating a growing capacity in understanding and learning. Participants spoke to the importance of personal stories to provide context to a particularly complex issue. The importance of networking and collaboration is associated to the ability to share knowledge and strategies, providing the opportunity to develop better and more well informed approaches to FASD. Opportunities to collaborate also inspire participants to work toward reconciliation via safe and supportive spaces to develop cultural awareness.

Key Findings

The following key findings were extracted from the notes and feedback of participants. All material was reviewed and coded for themes and those themes were then organized into key findings.

1

Culturally and Historically-Informed Practices

“Staff need to be trained in culture, FASD, and cognitive disabilities”

Many participants commented on the lack of culturally-informed training and programming available within professions and the broader community. One participant noted that, while there is basic training for police officers and other professionals, that the available training doesn't meet the needs of front-line professionals across agencies. Participants noted that there is a need to incorporate culturally-specific education early for professionals as *“staff need to be trained in culture, FASD and cognitive disabilities.”* Participants noted that collaboration with the community and Indigenous partners is important when developing programming and training protocols to ensure that the training is responsive to community needs. In the absence of culturally and historically informed training, participants noted that stigma and misinformation continues to surround FASD and is perpetuated by front-line professionals.

Participants suggested that culturally-informed and specific practices were lacking across systems. The TRC Call to Action 34 specifically points to the need for culturally-informed programming within the justice system; groups also discussed the need for those practices, training, and programming across systems. For example, participants identified the need for culturally-informed diagnoses, as the diagnostic practice is often experienced negatively by individuals and families. Attendees discussed the specific practice of diagnosis employed by Dr. Lori Cox, who utilizes a Medicine Wheel approach to explore FASD diagnoses with families and individuals. Participants also identified that circles for support would be a valuable addition to providing support to individuals and families across systems.

Participants also noted that prevention messaging can be experienced as insensitive by families and individuals. The evening event featured candid discussion among parents and caregivers about how prevention messaging can perpetuate stigma and misinformation about FASD. Participants noted that prevention messaging should be developed in conversation with the community in which it is distributed, to ensure that the messaging resonates with community understandings and experiences.

Trauma

“The greatest challenge is breaking through the shame”

Participants explained that trauma is often reinforced within systems. The diagnostic process was identified by many participants as a potential source for re-traumatization. For individuals who have experienced trauma, particularly trauma co-occurring with substance use, *“language associated with Aboriginal women”* and FASD brings forth automatic assumptions regarding alcoholism. For example, one participant noted that the language *“fetal alcohol”* places blame on the mother. Similarly, one participant noted that the label *“birth mother”* furthers stigma and pain as there is guilt associated with a FASD diagnosis. This blame can be experienced by mothers and families as traumatic, and participants noted the potential to improve the delivery of FASD diagnoses to prevent the experience of re-traumatization.

Participants also noted that trauma is normalized within systems and society as a whole. Indeed, the terms “trauma” and “trauma-informed” have been used extensively in the recent past, diminishing the potency of the word and the real impact trauma can have on an individual’s life. It was recommended that individuals heal through a restoration process of reconnecting with culture. Forming such a connection can have positive impacts on an individual’s identity, as connection to culture can help to root an individual in their heritage as opposed to rooting themselves in their disability. Many participants echoed that trauma-informed practice must be implemented in the community and within systems, which would combat stigma and trauma for families, by acknowledging trauma and its impact.

Participants also spoke about the need to empower individuals in the community. There is a need to *“teach the truth”* and to open honest conversations about the causes of FASD as they relate to reconciliation, such as *“colonialism, residential schools and inter-generational trauma.”* This history must be recognized and discussed in order to properly heal. Until we can have honest conversations, and acknowledge the roots of intergenerational trauma, similar to Residential School Survivors, we will not be able to effectively tackle the issue of FASD and its effects in Indigenous communities. Open dialogue such as this is one simple way to promote reconciliation. Badry and Wight Felske (2013) explain, “... alcohol use is not just about alcohol. It is also about stress, context, isolation, general health, age, genetics, resilience, cultural discrimination, exposure to violence, abuse, access to prenatal care, grief and loss, social policy and poverty” (p. 4). Indigenous populations might be more likely to experience some of these issues, often as a direct result of colonialism, residential schools, and intergenerational trauma.

One participant spoke about the need to incorporate Indigenous justice practices such as sentencing circles and/or healing circles, which are aimed at seeking reconciliation for and between individuals and within communities. Such an approach facilitates further opportunities to connect individuals impacted by FASD with cultural roots, never taking the focus away from the issue of FASD, but reminding people that they are more than this disability. As one participant so eloquently stated, *“we need to change the system to fit the individual instead of fitting the individual into a broken system.”* Another participant noted, *“the greatest challenge is breaking through the shame”* and one way to break through the shame is to be culturally and historically informed. Incorporating Indigenous approaches to justice and

healing may be a way to remind people *“it’s okay to need and use supports.”* Indeed, the TRC report and Calls to Action suggest that a move needs to be made toward an Indigenous system of justice.

3

Advocacy

“Begin the conversation, sustain the dialogue, diminish the shame”

Many FASD support agencies and parents of children with FASD report that the first step to creating both policy and societal changes regarding FASD is opening a dialogue. As individuals, agencies, and policy creators, we need to *“start the discussion and keep the conversation going”* because as one participant noted: *“the best way to increase public awareness and introduce prevention efforts in a tangible and supportive way is to talk about FASD,”* and continue talking about FASD until the stigma is diminished. As partners in health, justice, and education, one policy analyst noted the need for stakeholders to *“strategize solutions to combat the blame, [and] shame”* so people can and will *“access supports and programming.”* If shame discourages individuals or their families from pursuing diagnosis, or utilizing helpful programming which may assist the person with FASD to build on their strengths, programming does not matter.

This is already occurring in isolated communities and networks; families and agencies are requesting referrals to the Asante Centre and other FASD experts, as well as pushing for access to records and information in a timely manner. Some organizations are bringing FASD experts to communities to increase public education, and to allow individuals to *“remain with their support networks in their home communities.”* These

grassroots initiatives and self-advocacy efforts highlight how individuals, families, and workers are challenging current modes of support and diagnosis for individuals with FASD.

In order to address FASD across all systems (including health, justice, social services, and education) one participant noted the need to *“reframe FASD as a global issue”* not just an issue assumed to affect *“Indigenous peoples in colonial states.”* Prevention messaging must target all risk groups of which *“ethnicity is not the only demographic.”* Yet, this messaging should also be culturally appropriate for a broader audience.

Indigenous people have the *“right to decide what [messaging] is best for their own communities.”* Indigenous people, and mothers of children with FASD, need a place in the conversations about prevention and intervention. This would be an opportunity to acknowledge the many times that these perspectives have been marginalized which then is also an opportunity to promote reconciliation and healing. Healing may be needed: in regard to the loss of a child’s potential; from the stigmatization of the FASD diagnosis; and as communities and families so we may all *“move forward together.”*

The majority of participants echoed the need for FASD *“cause and awareness support.”* There are community champions in isolated pockets taking up the work of FASD education, prevention, and diagnosis. If we can respectfully increase awareness, and decrease the stigma attached to diagnosis, we can ensure those with FASD are able to access the resources they require. As a physician participant noted: *“it is the right of persons with disabilities to get the resources they need.”* However, governments need to buy-in to the work being done in communities and further support these ongoing efforts.

Resources

“It is not ethical to have no resources after diagnosis. But, there are currently no resources until you can PROVE your diagnosis”

Many participants expressed concerns with being able to effectively move forward when faced with the barrier of access to medical resources, diagnosis, funding, and education. Also mentioned was the inability for individuals to access the services they require due to waitlists and understaffing, especially for individuals in northern or rural communities. One participant noted the competition for funding as an inhibitor for improvement: *“Departments and Ministries are struggling and competing for resources across sectors (i.e., Education and Justice competing for programming funds from the same pool of government money) when they both require the funds to address FASD in these sectors.”* Once again, this statement draws attention back to the importance of interagency collaboration to develop well-funded and effective services for FASD.

Others noted a need for more resources to be allocated for access to costly medical records and diagnosis, as a diagnosis is often required before an individual can receive supports and other programming. However, one participant indicated, once a diagnosis is given the proper services may still be unavailable: *“It is not ethical to have no resources after diagnosis. But, there are currently no resources until you can PROVE your diagnosis.”* The question of ethics is raised when we are unable to provide for individuals in any capacity due to a lack of resources for the required level of support.

Interagency Collaboration

“Silo effect”

Many participants commented that there is a need for more interagency collaboration. It was noted there is currently a disconnect between health, education, and justice ministries, resulting in what is often identified as a *“silo effect”* between the systems that serve individuals with FASD. It was echoed throughout the conference that, if relationships rooted in open and effective communication between these systems are built, agencies would be able to better support individuals, families, and the broader community through more holistic approaches to client needs. One participant spoke about bridging the gap between agencies and specifically bringing legal aid, family and child services, alcohol and substance abuse services, and the justice sector together to work with individuals with FASD. An effective strategy to bridge this gap is to offer regular events that promote collaboration and networking.

Participants further discussed that collaboration must also occur between systems and community wherein the community has the opportunity to communicate their experiences to workers, and agencies can provide resources and information *“back to the community.”* Participants also noted that it is critical that community members *“know the services available”* which is often a barrier when there is a lack of collaboration between professionals and community members.

Furthermore, participants noted that an alliance between local, provincial/territorial, and federal governments must be made to reach the goal of appropriate and effective

intervention, prevention, and diagnosis. It was echoed throughout the Symposium that geographical jurisdictions should be sharing information with each other. This sharing would provide an opportunity to learn from each other and to build larger “*networks of support*” in “*intervention, prevention, and diagnosis.*”

6

Challenging Policy/Systems

“Reconciliation is not an Indigenous issue alone”

Participants identified barriers within policies and systems, which can negatively impact the lived experience of individuals with FASD and their ability to access appropriate supports. Specifically, participants discussed the limitations that are inherent to the current diagnostic guidelines in Canada, which rely on maternal confirmation of prenatal exposure to alcohol in the absence of the three sentinel facial features. In communities where supports are available for individuals with FASD, a formal diagnosis is often required to access these services. One front-line participant remarked how individuals with FASD are trapped in a cycle where they know they have FASD “*but cannot access the support and resources they need without their mother’s confirmation [of alcohol consumption]*” needed to receive a diagnosis. Instead, participants discussed how clinicians should be granted a “*broader ability to determine a mother’s drinking,*” while

“utilizing clinical observations more, in order to decrease the reliance on self reporting.”

It should be noted that this does raise ethical issues as it relates to the agency of mothers. Additionally, participants discussed the role of culturally-specific practices within medical systems as a means to confront the shame and blame which can prevent women from confirming prenatal exposure to alcohol. These new diagnostic techniques require buy-in from governments, their policy advisors, clinicians, and frontline workers. While FASD “*is not an Indigenous issue alone,*” participants discussed the importance of diagnosis practices to be responsive to community needs.

Participants also focused on the overrepresentation of individuals with FASD in the criminal justice system. Participants discussed how the expectations set upon individuals who come into contact with the justice system may reinforce the cycle of offending. For example, offenders with FASD may breach their jargon laden Conditions of Release due to lack of understanding or lack of support in the community, which would promote compliance. To sustain compliance and to break the cycle of reoffending, participants noted that court orders and release conditions should be “*in plain language that is clear and understandable*” and that jargon-free court orders should be “*standard across [Canada].*” It was noted that the justice system requires a “*paradigm shift*” and these changes may seem “*uncomfortable and unconventional*” but they are essential for the success of clients with FASD.

Recommendations

Each key finding is contextualized below, identifying the main action that needs to be taken, followed by the recommendations associated to the six key findings.

1

Culturally and Historically-Informed Practices: Giving Context to the Issue

Recommendation 1: The TRC Calls to Action request individuals and agencies to take up the work of reconciliation. Agencies should work to establish relationships with Indigenous peoples, including elders and knowledge keepers using culturally appropriate protocols. Relationships between agencies and Indigenous communities must be fostered with the goal of creating long-term sustainable relationships. Such relationships should be rooted in respect and dignity.

Recommendation 2: Community organizations and agencies working on FASD prevention and intervention should engage in TRC trainings and develop literacies about the history of residential schools and colonialism in Canada, to better understand the complexities and often deep-rooted causes of FASD.

Recommendation 3: Stakeholders should strive to explore the potential for culturally and historically informed practices within the health system. Integrated tools exist and others can be developed which has the potential to help foster collaborations in the area of diagnosis,

prevention, and supports. This should be done in consultation with community members, health workers, elders and/or knowledge keepers.

2

Trauma: Addressing the Past and the Future

Recommendation 4: Develop and distribute training on trauma-informed practices that are sector- and context-specific. Such training could help to understand the complex nature of FASD as a lived experience, as well as trauma associated to diagnosis.

Recommendation 5: Undertake a review of current justice practices to establish the capacity for trauma to be incorporated as a mitigating factor in sentencing. To consider trauma as a mitigating factor would mean to consider the intricacies of living with FASD.

Recommendation 6: In consultation with Indigenous health and wellness experts and researchers, develop outreach and training material for frontline health professionals about practices surrounding diagnosis and care. Culturally informed health practices would further promote goals of reconciliation and cultural sensitivity.

Advocacy: Heightening Awareness and Reducing Stigma

Recommendation 7: Facilitate collaborative spaces that are inclusive and welcoming of candid discussions, with the goal of reducing stigma and silence that are often associated to FASD.

Recommendation 8: Create spaces for individuals with FASD and caregivers to engage directly with policy-makers and program managers to inform changes to policy and practice based on lived experience. This would result in more effective and practical programs and services.

Recommendation 9: Facilitate spaces for individuals with FASD and families to access appropriate and desired training. Such training could help individuals to access much needed resources.

Recommendation 10: Recognize the unique and important perspectives of Indigenous mothers and families. Implement and integrate changes to programs and practices that honour their perspective as it relates to parenting more broadly as well as prevention and intervention practices for those living with FASD. Incorporating and respecting Indigenous worldviews is essential to opening and maintaining dialogue rooted in healthy relationships.

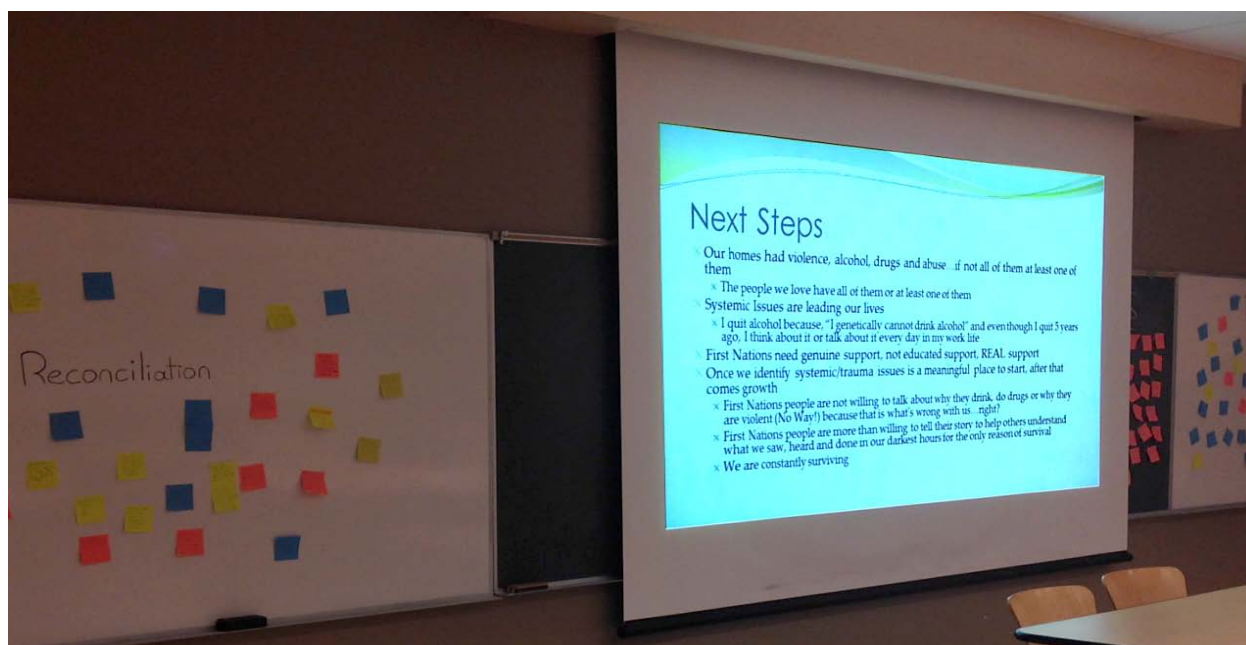
Recommendation 11: Keeping families together should be a top priority informed by many perspectives, including those of Indigenous mothers, which is consistent with Call to Action 1(ii). In acknowledging a variety of perspectives, we can create holistic approaches to not only FASD, but the institution of the family.

Resources: Filling Gaps in Service

Recommendation 12: In consultation with Indigenous health and wellness experts and researchers, identify wise, culturally-informed practices that best support individuals with FASD across the lifespan. Following consultation, distribute to appropriate Federal, Territorial, and Provincial partners for enhanced program supports and services, aimed at a wide array of age groups.

Recommendation 13: Prioritize community driven requests for supports and services with an emphasis on sustained funding for programs and services that support individuals and families with FASD. In trusting the community to know what they need, more effective services can be delivered. Moreover, this recommendation in combination with greater interagency collaboration will ensure funding is used effectively and efficiently.

Recommendation 14: The legacy of residential schools and ongoing impact of trauma on individuals and families necessarily requires additional funding to best support individuals with FASD through a range of programs including but not limited to: enhanced culturally appropriate diagnoses, mentorship and respite for families, life-skills and mentoring for individuals, and ongoing support that changes across the lifespan.



5

Interagency Collaboration: Combatting the Silo Effect

Recommendation 15: Facilitate regular opportunities for interdisciplinary teams to come together to share resources with the goal of bringing about cross-sector-informed changes to practice. Such opportunities will help to diminish the silo effect, effectively breaking down barriers to communication and collaboration.

Recommendation 16: Strike working groups comprised of federal, provincial/territorial stakeholders, and policy-makers with an explicit goal of making recommendations to implement TRC Calls to Action 33 and 34. Teams will necessarily take direction from Indigenous leadership and open and maintain dialogue with Indigenous parents and front-line workers, to inform recommendations in a culturally appropriate manner.

6

Challenging Systems and Policy: Fighting Barriers to Access

Recommendation 17: Undertake program and policy review through a TRC lens to make appropriate modifications to programs, practices, and protocols to best address the complex and individual needs of those with FASD.

Recommendation 18: Undertake a review of culturally modified/culturally appropriate diagnostic practices to modify or enhance current diagnostic practices, to enhance access to services and available supports.

Conclusion and Path Forward

Knowledge on FASD has been shifting from baseline inquiries of what FASD is, to what we can do to address it. The release of the TRC Calls to Action has given context to a complex issue, demonstrating our shifting collective knowledge base on FASD. The conversations are no longer limited to learning about this complex disorder, and have now shifted to acknowledgement of the complexities underlying a disorder that is not only rooted in health, but also justice, education, and a wider social context. This in itself should be a celebrated occasion. However, as a collective of researchers, policymakers, community agencies, and those with FASD and their caregivers, this Symposium has highlighted the need to continue our learning and growth in relation to FASD.

Key findings suggest interagency collaboration is imperative to our ability to help. Moving out of silos would contribute greatly to holistic practices and services, keeping in mind the importance of open dialogue, and not excluding Indigenous populations. Moving forward, there is a pressing urgency to fight barriers to access via challenging systems and policies. Changes need to be made to diagnostic practices to ensure greater access to services. In regard to justice, simple steps can be taken such as adjusting the wording in justice decisions to make such documents accessible, ensuring greater success rates for those who come into contact with the justice system. There is a need to give context to FASD that is culturally and historically informed. Forming respectful and enduring relationships between Indigenous peoples, agencies, and policy-makers can lead to better understanding of the traumatic history of colonialism and its lingering impacts.

Moreover, such relationships will assist in developing culturally-informed practices for those living with FASD. Both the past and the present need to be addressed in relation to any trauma that is interwoven through history. Trauma informed practices should be employed, and FASD should be considered as a mitigating factor within the justice system. Again, through stronger relationships, there is greater potential for culturally informed health practices.

Advocacy is imperative to raising awareness of FASD and reducing the stigma surrounding this disorder. Candid conversations need to occur. Those with FASD and their caregivers need to be consulted on policy and program development. These same individuals need access to training. Indigenous perspectives on parenting should be respected and acknowledged in prevention and intervention strategies. Ultimately, the goal should always be to keep families together. Finally, resources need to be accessible. Collaboration with Indigenous experts is essential in creating culturally-informed services for those with FASD. Community-driven requests for services must be acknowledged and responded to including the need for enhanced culturally appropriate diagnoses, mentorship and respite for families, like-skills and mentoring for individuals, and ongoing support that changes across the lifespan.

Indeed, we have the capacity to “*move forward together*,” but a commitment must be made toward greater collaboration between agencies and between cultures. It is when respectful and sustainable relationships are developed that the TRC Calls to Action will become effective, essentially moving us from *truth to reconciliation*.

Appendix 1: Schedule

Day One

Laying the Foundation	
8:00 am	Registration and Coffee
8:30 am	Formal Welcome and Opening Comments <ul style="list-style-type: none"> • Dr. Vianne Timmons, President of the University of Regina • Noel Starblanket, Knowledge Keeper and Life Speaker • Introduction of speakers and go around (all participants)
9:30 am	Research & Event Overview <ul style="list-style-type: none"> • Dr. Michelle Stewart, University of Regina
10:00 am	Coffee and Networking Break
10:30 am	Mapping the Issues <ul style="list-style-type: none"> • Where are we now? • Where do we want to go? • What is needed to get there?
12:00 pm	Lunch and Networking Break
Holistic and Culturally-Safe(r) Approaches to Programs and Practices	
1:00 pm	Roundtable One: Holistic and Culturally-Safe(r) Approaches to Programs and Practices <ul style="list-style-type: none"> • Lisa Lawley, Kermode Friendship Centre (BC) • Rachel Tambour, Tree of Peace Friendship Centre (NWT)
2:30 pm	Coffee and Networking Break
3:00 pm	Guided Discussion <ul style="list-style-type: none"> • Can practices change and how?
4:00 pm	Adjourn for the day
Evening Event	
7:00 pm to 8:30 pm	FASD: Tackling Stigma in Daily Life *Free Public Event hosted at the Ramada Inn

Day Two

Taking up the Challenge: Legal Considerations	
8:00 am	Registration and Coffee
8:30 am	Roundtable Two: Taking up the Challenge: Legal and Ethical Considerations <ul style="list-style-type: none"> • Laura Hoversland, Justice Manager for Council of Yukon First Nations (YT) • Samaya Jardey, Through an Aboriginal Lens (BC)
10:00 am	Coffee and Networking Break
Bridging by Fostering Culturally-Safe Collaborations	
10:30 am	Roundtable Three: Bridging by Fostering Culturally-Safe Collaborations <ul style="list-style-type: none"> • Lisa Workman, Four Direction Community Health Centre (SK) • Dr. Lori Cox, Eastern Door Diagnostic Team (NB)
12:00 pm	Lunch and Networking Break
New Perspectives on Tough Questions	
12:45 pm	Table Top and Guided Discussion <ul style="list-style-type: none"> • What are the big take away items? • Are there new strategies and skills to take on tough questions and the work of reconciliation? • What are the next steps to expand this work?
2:15 pm	Closing Comments
2:30 pm	Event Ends

Appendix 2: Biographies

Lisa Lawley

Kermode Friendship Center British Columbia

The Kermode Friendship Society brings awareness, education, and prevention of Fetal Alcohol Spectrum Disorder to communities and families. They provide support, mentoring, healing from trauma and substance abuse, family planning, and referrals to other community services. Lisa recognizes that mothers need empowerment and support to overcome the shame and stigma that comes with a child's diagnosis of FASD to move forward in making positive lifestyle changes. Lisa and the team at Kermode provide a safe space that is free of judgment for people to come together to heal.

Rachel Tambour

Tree of Peace Friendship Centre Northwest Territories

Rachel is a service provider and caregiver who works with the Tree of Peace Friendship Centre in Yellowknife. Rachel not only works professionally with individuals living with FASD, but also advocates as a parent of a son living with FASD and is knowledgeable about the stigmatization associated with a diagnosis. Rachel aims to challenge “the shame, the blame, and the stigma” of Fetal Alcohol Spectrum Disorder by assisting other women to overcome challenges and encouraging honest discussions about the effects of alcohol and pregnancy.

Laura Hoversland

Justice Manager for Council of Yukon First Nations, Yukon Territory

Laura's position in the legal field and recognition of the challenges faced by First Nations people has contributed to her work in Whitehorse, Yukon. Laura was given the opportunity to work with First Nations people in the justice system as an Aboriginal Courtworker, and soon after accepted the position as Justice Manager in her department. Laura's life growing up in small town Yukon and her understanding of the burdens faced by First Nations people contribute to her work in alleviating these burdens for those in her community.

Samaya Jardey

Through an Aboriginal Lens British Columbia

Samaya works directly with former Indian Residential School students and their families, and is committed to addressing the intergenerational trauma caused by residential schooling. Samaya has brought together various partnerships as Program Manager for Through an Aboriginal Lens, which seeks recovery from the effects of systemic racism and residential schools. Youth and families referred to the Youth Justice FASD program are provided guidance and comprehensive support from the team at Through an Aboriginal Lens.

Lisa Workman

Four Directions Community Health Centre Saskatchewan

Lisa has an education degree from the University of Regina, with which she taught throughout Saskatchewan before accepting a position in community development in inner-city Regina. Today, Lisa is at Four Directions Community Health Centre where she is the Aboriginal Community Development Coordinator. In addition to her position at Four Directions, she is also the chair of the Regina FASD Community Network.

Dr. Lori Cox

Eastern Door Diagnostic Team New Brunswick

Dr. Lori Cox is a member of Elsipogtog's Eastern Door Diagnostic Team in the Maritimes. She is active in research, diagnosis, screening, assessment, and intervention of FASD through a “Medicine Wheel” model. Dr. Lori Cox also works in schools with children who have been prenatally exposed to alcohol, in addition to high-risk youth and families affected by FASD. She is a primary author of the SOGC guidelines for physicians, co-authored a book for Justice Professionals, and is currently working on building an FASD curriculum at UNB College of Extended Learning.

Appendix 3: Evaluation Questions

Pre-Event Survey

The pre-event survey comprised four questions:

1. Please describe your role.
2. Why did you want to attend this event?
3. What do you think is the most pressing issue when discussing FASD and Reconciliation?
4. What are some of the challenges you face as it relates to FASD and Reconciliation?

The survey responses indicated that the participants of the FASD, Justice, and Reconciliation Symposium included policy-makers, program directors and managers, advocates, researchers, caregivers, and front-line professionals.

The primary reasons that participants identified for attending the event included to learn more about FASD, to learn about the programs and initiatives taking place in other jurisdictions, to learn about best practices, to influence policy, and to establish partnerships with other professionals and engage in networking activities.

Participants had diverse responses when identifying the most pressing issues and challenges they face in their work in relation to FASD and Reconciliation. Common responses included: lack of resources, the stigma surrounding FASD, lack of programming, lack of awareness, lack of knowledge, and justice-specific challenges.

Day One Survey

Participants were asked to rate, on a scale of 1-5 with 1 being the lowest and 5 being the highest, the overall utility of the information presented in the morning session.

Of 45 responses, 42% of participants responded with 5, 47% of participants responded with 4, and 7% responded with 3. One participant was absent for the morning sessions and thus did not provide a response, and one participant responded with 1.

Participants were asked to rate, on a scale of 1-5 with 1 being the lowest and 5 being the highest, the overall utility of the information presented in the afternoon session. Of 45 responses, 53% of participants responded with 5, while 44% of participants responded with 4. One participant responded with 1.

Participants were asked to rate, on a scale of 1-5 with 1 being the lowest and 5 being the highest, how they felt that the group discussions helped further their own knowledge and understanding of the issues. Of 45 responses, 64% of participants responded with 5, and 31% responded with 4. One participant responded with 1, and one participant responded with 2.

Participants were asked what could be changed for day two. There were tangible requests such as smaller tables, longer or shorter breaks, and more discussions time. When asked to share any additional thoughts, the response from participants was positive overall. Participants expressed appreciation for the diversity of attendees, the presentations, the opportunity to network, and the facilitated discussions.

Day Two Survey

Participants were asked to rate, on a scale of 1-5 with 1 being the lowest and 5 being the highest, the overall utility of the information presented in the morning session. Of 39 responses, 72% of participants responded with 5, while 28% of participants responded with 4.

Participants were asked to rate, on a scale of 1-5 with 1 being the lowest and 5 being the highest, the overall utility of the information presented in the afternoon session. Of 39 responses, 69% of participants responded with 5, while 31% of participants responded with 4.

Participants were asked to rate, on a scale of 1-5 with 1 being the lowest and 5 being the highest, how they felt that the group discussions helped further their own knowledge and understanding of

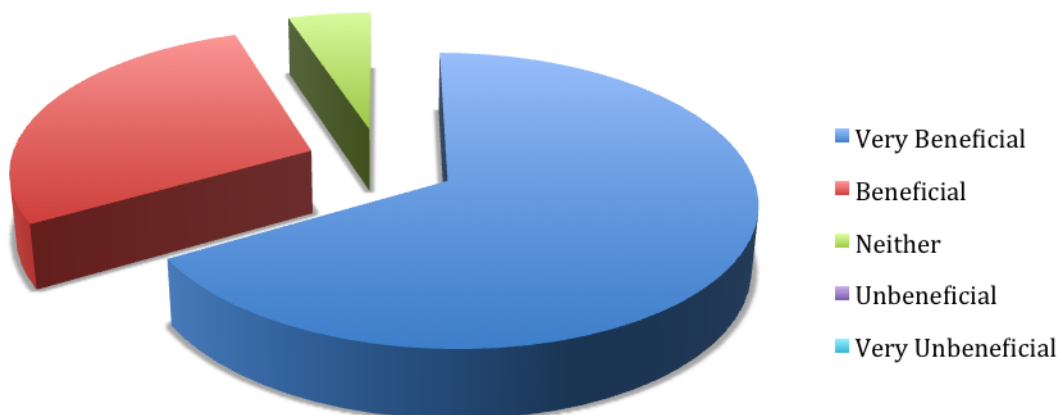
the issues. Of 39 responses, 69% of participants responded with 5, 27% responded with 4, and 5% of participants responded with 3.

When asked to explain their responses, participants identified that the networking among participants was invaluable. Many participants felt that the presentations were informative and valuable. Participants also identified that the event was well-organized, and that the facilitated discussions were helpful. Participants enjoyed the balance between presentations and time to discuss issues with other participants.

Participants were asked to rate, on a scale of 1-5 with 1 being the lowest and 5 being the highest, how they would rate the event overall. Of 39 responses, 72% of participants responded with 5, and 28% of participants responded with 4.

Participants were asked to rate, on a scale of 1-5 with 1 being the lowest and 5 being the highest, whether the event was beneficial to them in the work they do or the role they have. Of 39 responses, 67% of participants responded with 5, 28% of participants responded with 4, and 5% responded with 3.

Benefit to Participants' Work



Satisfaction with Event



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This report is intended to capture the discussions and input of a wide range of participants that attended the Symposium. It is intended to include details from the event but is not exhaustive — any errors or omissions are those of the authors.

Acknowledgements

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For More Information

For more information about Dr. Stewart's research project focused on FASD please visit the project website by scanning the QR code on the back cover or going to fasdresearchproject.com.

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