

# Policy Webinar Report

## Enhancing Culturally Safe and Trauma Informed Approaches to Assessment and Diagnosis Practices

This event was intended to stimulate discussion for policy makers and enhance understanding of Fetal Alcohol Spectrum Disorder (FASD) as a disability; the importance of diagnosis; diagnostic components; processes and structures in Canada; strengths and needs of diagnostic assessment clinics; insights from the National FASD database; and considerations for culturally safe practices in the clinic setting.

This report will provide an overview of the webinars and summary of the policy discussion. Canada FASD Research Network (CanFASD) is honoured to support the efforts to improve the outcomes of individuals with FASD through this webinar series.

**Facilitator:**

Mr. Darren Joslin worked for the Government of Alberta for 31 years in the Social Services and Health sectors. His work focused on a number of different areas including Fetal Alcohol Spectrum Disorder (FASD), Mentoring and Youth Homelessness. He was the Co-Chair of the Alberta FASD Cross-Ministry Committee during the development and initial implementation of Alberta's FASD 10-Year Strategic Plan. As a member of the Canada Northwest FASD Partnership he was involved in the establishment of the Canada FASD Research Network.

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# Executive Summary

The Canada Northwest Fetal Alcohol Spectrum Disorder Partnership (CNFASDP) is made up of Ministries addressing FASD from the 4 western provinces and 3 territories. The Partnership's 2021-2023 Strategic Priorities highlight a number of areas that the Partnership would like to explore in more depth to understand how the evidence might be utilized to inform policy. One of these strategic priorities is enhancing culturally safe and trauma informed approaches to FASD assessment and diagnostic practices. Services need to utilize approaches tailored to individual and local situations as all communities, including Indigenous communities, are unique with their own history and experiences. The Steering Committee of the CANFASDP contracted the Canada FASD Research Network to assist with planning and organizing meaningful discussion with experts to help understand the opportunities and challenges in having culturally informed approaches to FASD assessment and diagnosis.

A series of virtual presentations were organized to inform and stimulate conversation with policy makers. One of the presentations (understanding diagnosis) had broad appeal and was opened up to the public but the remainder of the presentations were set up only for policy makers. The public presentation had about 150 participants while the other policy presentations had about 20-30 participants which allowed for a more thorough discussion.

The series began with building understanding of the FASD diagnostic criteria, what is assessed, and how the clinics typically operate. Canada is one of the few countries in the world with FASD diagnostic guidelines and it is important to have this base

knowledge of the process prior to discussing more complex elements such as culturally safe and trauma informed practices.

The second presentation highlighted new qualitative research with 10 FASD diagnostic clinics in Canada that looked at their challenges, opportunities, practices for cultural inclusivity, clinic strengths and needs. This first-hand account from clinics was valuable, outlining how they do their work and what they need from governments including recognition for the work they do and sustainable funding. The clinics shared many strengths that they have such as resiliency, the innovative ways they do more with less, community engagement and partnerships.

Dr. Cook presented on the National FASD Database to the CNFASDP Steering Committee, sharing insights into the over 4000 files in the database, entered by most of the FASD diagnostic clinics in Canada. This unique and one-of-a-kind database has over 600 data points that can be explored, including a breakdown by ethnicity. Risk and resiliency factors as well as vulnerabilities are important information that is available for policy makers for individuals that self-identify as Indigenous and is otherwise not available to them for this unique and vulnerable population. CanFASD owns this database and is very cautious and careful about how and when this information is shared.

The fourth presentation was quite popular as it included three unique FASD diagnostic clinic structures that were all inclusive of Indigenous communities and practices. Although all the clinics were in different stages, ranging from 20 years to 3 years of operations, the common thread was rooted in good community development. For some it meant the First Nations community developed and operated their own FASD diagnostic services and some were central community-based but were inclusive of the First Nations and Metis communities in the area.

They shared their journeys, challenges, strengths and successes. This presentation provided a lot of insight of how best practices in this realm are operationalized.

The final presentation led by Dr. Tremblay helped pull these threads of the previous presentations together into a more specific discussion about culturally inclusive FASD diagnostic services. This was a very engaging and thoughtful presentation on considerations of respectful engagement with Indigenous communities, including some difficult but important conversations on the role of colonialism and service delivery.

Some of the overall key considerations for policymakers from these presentations include:

1. There is a need for a greater understanding of FASD and FASD diagnosis across governments, including the importance of diagnosis as it relates to better outcomes.
2. FASD diagnostic clinics in Canada have been resilient and creative, however, in order to be sustainable, stable supports including funding are critical.
3. Multi-disciplinary teams are imperative for effective FASD diagnosis, and to identify and engage appropriate support services.
4. Canadian FASD diagnostic clinics are more successful when they adapt to the community/regional needs.
5. Multi-disciplinary FASD diagnostic teams need to be connected to and have an understanding of the community they serve.
6. New FASD diagnostic services need training and mentorship.
7. Relationships between FASD diagnostic clinics and community stakeholders is critical.
8. Indigenous communities should be involved in FASD diagnostic service development and delivery.

9. FASD diagnosis needs to be linked to support and/or intervention services as these links greatly improve outcomes for people with FASD, their families and support systems. FASD diagnosis can also provide information to justify an individual's need for these supports or intervention services.
10. The CanFASD National FASD Database has information that may assist in better understanding the health and social needs of Indigenous patients.

### **Implications for Policy**

Several policy recommendations emerged from this webinar series, which would support the continued enhancement of culturally safe and trauma-informed approaches to assessment and diagnosis practices:

1. Develop and implement funding mechanisms that can be accessed by community groups to establish diagnostic clinics, including recommendations and standards for training and mentorship.
2. Develop a guide that outlines considerations for culturally relevant and community engagement with communities for the development or use of FASD diagnostic services.
3. Identify funding to explore the Indigenous-specific research in the National FASD Database to determine the unique health and social needs of this population.
4. Consider collecting information for Indigenous families about their experiences with FASD diagnostic services and how they can be improved, sharing this information with the diagnostic clinics for improvement.
5. Consider asking FASD diagnostic clinics how the increased capacity for service might be achieved.
6. Developing dialogue with other government departments that may have the capacity to develop and deliver FASD



diagnostic services such as youth and adult corrections, education, forensics, mental health facilities and child welfare.

### **Webinar #1: Understanding FASD diagnosis and process**

**February 18, 2022, for public**

#### **Presenters:**

*Dr. Hasmukhlal (Hasu) Rajani, FRCPC, Pediatrician has been a core clinic member of the Lakeland Centre for FASD (AB) diagnostic team since 2000, as well as with the Northwest Central FASD Network and Northeast Alberta Network Assessment and Diagnostic clinics. He provides clinic training and mentors and educates government agencies and FASD Assessment and Diagnostic Clinics through presentations that strengthen their ability to provide consistent diagnostic and supportive services. Dr. Rajani is a General Pediatrician doing community consultative pediatrics out of Northeast Community Health Centre in Edmonton; appointed as Professor in the Department of Pediatrics; teaches residents and students in the ambulatory and inpatient setting; and does outreach pediatric consultation clinics in several small AB communities. Currently Dr. Rajani is also the Director (interim) of the Division of General Pediatrics and the Zone Clinical Chief (Interim) of Community Pediatrics Faculty of Medicine and Dentistry, University of Alberta.*

*Colleen Burns, Lakeland Centre for FASD, AB is the Clinic Training Services Coordinator for the Rajani Assessment and Diagnostic Clinic Training Services since 2011. She has facilitated training and community practice events and develops resources for FASD clinic teams. Connecting with clinics across jurisdictions and working with a committed team of clinicians drives her work.*

The video is available [here](#).



**Overview:**

Reviewing the FASD diagnostic clinic process begins with the referral and intake, each clinic sets referral criteria for clinics such as age, previous assessment information required, and application form. Quite a lot of information is collected at this stage to ensure the clinic team has the relevant information to inform the diagnosis. This includes family history, medical records, prenatal alcohol confirmation, education history, child protection involvement, justice, and employment history. Once the information is collected then the client/patient moves into the assessment phase with the psychologist, speech-language pathologist, occupational therapist, and physician. Each clinic has their own process on how this is completed – prior to clinic day, on clinic day, virtually, etc. The clinic team meets together to review the case history, previous and current assessments, and completes formulation of diagnosis and recommendations. The clinic team usually then meets with the family, support team and individual to share the results of the assessments, diagnosis, and recommendations. This is also an opportunity to educate, answer questions and identify the strengths of the individual. The completion of a medical summary report is then sent to the guardians and family physician.

These reports also include other significant findings such as other disabilities (learning, attention, etc), sleep concerns, sensory issues, emotional regulation, medical concerns, or notable areas that were identified by the clinicians. The key to effective FASD diagnostic process will be teamwork- clinicians sharing and debating the findings of assessment combined with the patient's history leads to a balanced and accurate diagnosis.

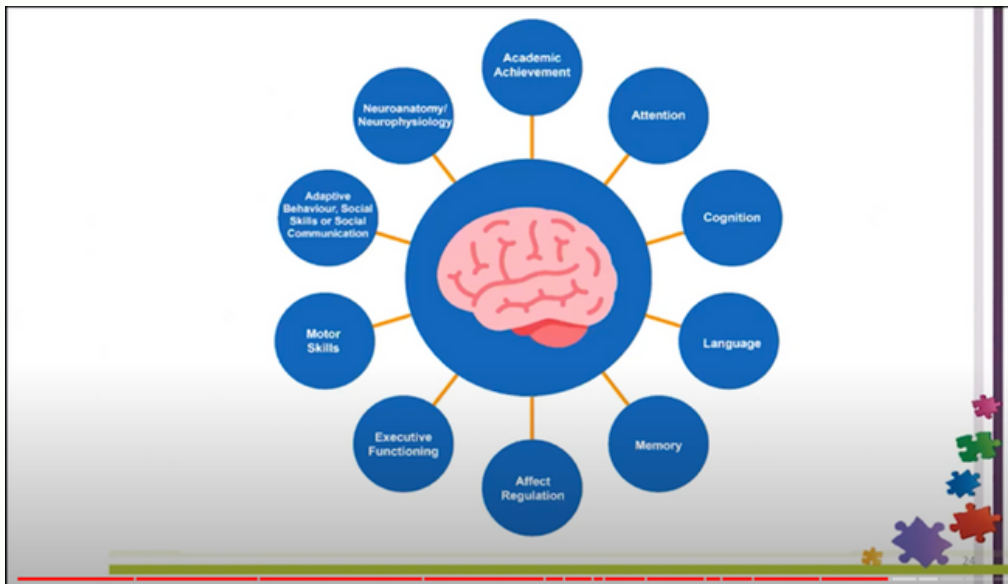
The Canadian FASD Diagnostic Guidelines overview can be found [here](#), and the details for clinicians can be found [here](#).

Dr. Rajani highlighted that the composition of the clinical team may vary depending on the age of the patient and the level of community involvement. The core pediatric team is usually made up of physician (nurse practitioner), OT, SLP, Psychologist, and clinic coordinator. The usual adult clinic team consists of a clinician (physician, nurse practitioner, psychiatrist), psychologist, SLP, and clinic coordinator. Community team members can play a crucial role in understanding the complexities of a community, know the services available, what their own organizations can provide and make linkages immediately for families, these could include: addiction counsellors, social workers, child protection, cultural interpreters, Elders/knowledge keepers, mental health, parent advocates, probation, teachers, and vocational services.

Prenatal alcohol exposure (PAE) during the index pregnancy is confirmed by the clinical team and is based on:

- Sources that are reliable and devoid of any conflict of interest, written confirmation is the best source from previous reports, with the exception of the mother sharing her own story.
- Conversations with the mothers to gather information about alcohol use during their pregnancy use a sensitive, non-judgmental, and trauma-informed approach.
- Unsubstantiated information, lifestyle alone, other drug use or history of alcohol exposure in previous pregnancies cannot, in isolation confirm alcohol consumption in the index pregnancy.
- The number and types of alcoholic beverages consumed (dose), the pattern, frequency, timing and duration of drinking should be documented.

Brain assessment is a key part of the FASD diagnostic criteria which covers 10 specific areas of the brain. Direct standardized measures should be used to assess brain domains whenever possible for the majority of evidence for brain dysfunction. Indirect measures of rating scales, clinical interview, or file review may need to be used at times. In order to meet the criteria for an FASD diagnosis, a patient's functioning in at least three brain domains are determined to be significantly impaired. Significant impairment is defined as two standard deviations below the mean level of functioning.



FASD diagnostic categories:

- FASD with Sentinel Facial Features
- FASD without Sentinel Facial Features

Designation:

- At Risk of Neurodevelopmental Disorder and FASD associated with Prenatal Alcohol Exposure

Key takeaways:

- Canada has specific diagnostic criteria for diagnosing FASD
- FASD diagnostic clinics in Canada are following the Canadian FASD diagnostic guidelines

- Diagnosis of FASD involves a multi-disciplinary team and assesses specific brain domains
- Clinics follow a similar process to arrive at the diagnosis

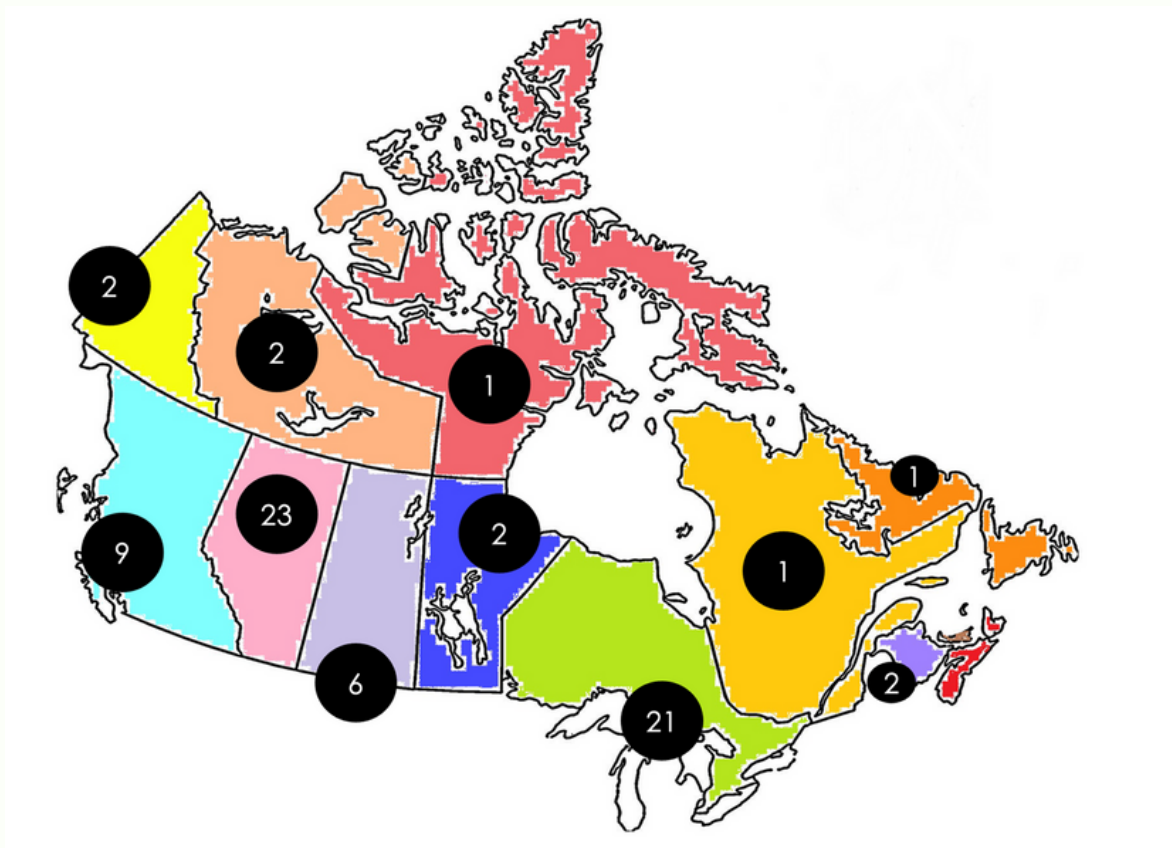
## **Webinar #2: What do we know about how FASD diagnostic services are organized in Canada?**

**March 24, 2022, policy only**

*Dr. Kelly Harding, PhD, is the Director of Research Administration and a Research Associate with the Canada FASD Research Network. She is also an Adjunct Faculty member in the Department of Psychology at Laurentian University. Kelly has a background in human development, interdisciplinary health, and health service delivery, particularly in rural and Northern communities. She has worked in the field of FASD since 2010 and is involved in diverse research projects in the areas of FASD prevention and women's health, FASD assessment and diagnosis, family well-being, mental health, and human rights.*

Examining the organization of FASD diagnostic clinics in Canada is new research that Dr. Harding has conducted. This work is not yet published but she was able to share the information with us to help our understanding of the complexity of the FASD diagnostic clinic landscape in Canada.

The importance of an FASD diagnosis provides access to supports and services; interventions and prevention of future births with PAE; multidisciplinary team identification of the individual's strengths; helpful information is collected throughout the clinic process to inform interventions; and people with an FASD diagnosis experience fewer adverse outcomes.



Of the estimated 70 clinics in Canada this is the provincial/territorial breakdown. It should be noted that the Manitoba network includes regional diagnostic coordinators across five health regions that work in partnership with the Manitoba FASD Centre. There may be new clinics that we are not aware of, and some clinics may be on hold during the pandemic. Clinics are organised in many different ways such as through a hospital, health authority, child development clinics, other health or justice facilities, community based, private clinics, or a combination of these.

Dr. Harding's study was to collect information about the establishment, operation, and practices of a select sample of FASD diagnostic clinics (n = 10) across Canada, and to understand how different clinics operate, as well as the similarities and differences between these varying structures. Twelve participants from ten clinics across Canada (5 pediatric clinics, 1 adult only clinic, and 4 saw pediatric and adults) were interviewed with the same questions; this information was then analyzed into three key topic areas to address the overall aims of the study: Barriers and Challenges; Establishment and Operations; and Evidence and Practice-based Recommendations.

Clinics identified Barriers and Challenges as:

- Limited diagnostic capacity
  - Clinics being able to meet the demand for diagnostic services, including increased demands for additional assessments and requests to expand the clinic to include other demographic groups (e.g., provide adult assessments)
  - Clinics may have limited numbers of assessments that they are able to provide
  - Pressure from community to conduct more assessments and/or wanting expanded criteria
  - Some clinics identified long waitlists and discussed the distress felt by having individuals wait several years for an assessment (e.g., "A 7-year-old doesn't have 2 years to wait to be diagnosed")
  - How do we train more professionals, obtain more funding, and hire more staff

- Funding limitations
  - Impacts clinics' ability to provide assessments but also follow up supports such as mentorship to families and outreach support to individuals
    - For clinics who had stable and consistent funding, participants expressed their latent concerns that funding could always be cut or lost at any time and described that funding was never a “for sure” thing
- Stakeholder and government interest and support
  - Large geographic disbursement and that funding is often centralized to large urban areas, making clinics feel as though resources are allocated elsewhere and they are often left to fend on their own
  - Perception that the federal government lacks interest in supporting Indigenous peoples in obtaining assessments and supports
  - Feeling that provinces are not viewing FASD diagnosis as a priority and that more uptake is needed
    - Would like some recognition that the work they do is important and that officials are knowledgeable about the value of this work

**Areas included in the research but not discussed in the presentation**

- Attitudes of others
- Human resources

“... now what's happening is we have to somehow meet the demand for diagnostic services.”



Clinics also identified important Strengths and Uniqueness to their clinics:

- Relational connections
  - “We are always, always looking for different ways to support our clients and their families.”
  - Adaptive and creative to find ways to support their families, by building and maintaining relationships with other community programs, working to maintain consistency in their client's lives, and always working to provide post clinic support that is individualized and personalized following the client across the lifespan
  - Clinic Coordinators were key to working with the communities and providing supports to share their news and building those key relationships (e.g., maintaining a strong connection to the communities coordinators lived and worked in)
- Culturally responsive approaches
  - “We make sure that we don't forget that cultural piece, the spirit of the client in itself. So I think that's unique to [our clinic] as well.”
  - Having an Elder who was knowledgeable about FASD who participated as the clinical team (e.g., an Elder who sat in on appointments, when desired, in some clinics; learning about the First Nations/Indigenous communities in the clinics' areas)
  - Build partnerships, representation, and buy in from communities to meet their needs
  - Maintaining relationships and helping each other to build better services
  - Clinics saw this responsibility as important to be culturally responsive, always thinking about how they can do this such as hiring an Indigenous physician, taking the clinic to the community vs having individuals traveling to a large community, and having clinical teams trained in the Indigenous communities in the service area and our colonial history

- Human resources
  - Clinics talk about doing more with less, with the “secret sauce” to their success being their clinic coordinators and their dedicated staff members
  - Clinic coordinators are the connection between the families/individuals, clinical teams, community resources, and community training
  - Clinics care about the people that they serve

“After each assessment, the team gets together to talk, so there's always opportunities to say, ‘**What can we do differently or better?**’ Like right now, we're getting too many assessments coming in ... I really want to get another physician, and **I would really like to have an Indigenous [physician].**”

I want to be able to use some of the [funding] ... and take our assessment team onto a reserve into their health units and spend a week, 2 weeks in their clinic, in their office, in their health office, to be able to do 15 assessments, or 10 assessment, **so that the Indigenous people don't have to come into our country to be able to be assessed.**

....

I think it's really important ... **if you even have one client** who has an Indigenous background, **that you are Indigenous aware.** You have to really **immerse yourself with the communities that are supporting individuals** who are Indigenous.”

#### Keys to clinic success:

- Build relationships with community stakeholders, including:
  - Gaining insights on the experiences of families and individuals
  - With Indigenous community members and Elders
  - Community service providers
- Build a cohesive team, including finding community team members to participate
- Prepare key stakeholders, including the general public, about the importance of diagnosis and the need for robust follow-up services for people who have FASD and their families
- Prepare politicians, including municipal and provincial, about why and what you are doing

Key takeaways:

1. Clinics face several barriers but are resilient
2. Clinics serve their community first and foremost, using a model that is best suited for the population that they serve
3. A good group of clinicians that make up the multidisciplinary team makes a world of difference to the effectiveness of the operations

### **Presentation to the CNFASDP Steering Committee: National FASD**

#### **Database information about Indigenous participants**

**March 23, 2022**

*Dr. Jocelynn Cook graduated with a PhD in Reproductive Physiology from the Medical University of South Carolina in 1997 and spent 10 years in an academic setting as graduate student, a post-doctoral fellow and an Assistant Professor. Wanting to expand her skillset beyond the basic science laboratory, she embarked on a Masters of Business Administration, and graduated from the University of Saskatchewan with an MBA, specializing in Economics and Health Policy. Her professional career has focused on issues related to maternal-fetal medicine; specifically, substance abuse during pregnancy, preterm birth, Fetal Alcohol Spectrum Disorder (FASD) and Assisted Human Reproduction. She has gained expertise in clinical research and issues related to clinical practice for pregnant women and their children and program evaluation, as well as experience with population and epidemiology research. Early on in her career, she became involved with Aboriginal Health research, especially as it related to the social determinants of health. This broadened her research perspective and she gained expertise related to suicide prevention, mental health and addictions, child development, communicable diseases, chronic diseases, health surveillance and National and International trends in morbidity and mortality.*

*Dr. Cook is an Adjunct Professor to the department of Obstetrics and Gynecology at the University of Ottawa, appointed in 2002.*

*Dr. Cook joined the Society of Obstetricians and Gynaecologists of Canada as its first Scientific Director in 2014 and oversees all work related to Continuing Medical Education, Clinical Practice Guidelines, Research, Accreditation, Global Health and Indigenous Health. She was the Executive Director of CanFASD from 2011-2014 and was instrumental in the development of the National FASD Database which is the only such database in the world.*

The National FASD Database is operated by CanFASD and led by Dr. Jocelynn Cook as the Principal Investigator. Clinics across Canada enter specific patient data into a secure database that is anonymized, and clinic blinded. This is a point in time collection of information and is not tracking individuals over time (i.e., it is a cross-sectional design). The data collected tells many important stories about Canadians that are being assessed by FASD diagnostic clinics, including types of diagnosis, physical and mental health co-morbidities, recommendations for interventions, experiences, specifics of the diagnostic criteria and demographics. This Database is the first National FASD collection in the world. It is used to inform practices and policies that address gaps in service delivery, trends and evidence about the individuals with FASD/prenatal alcohol exposure in Canada. It also provides a database where research questions can be answered.

The database has been used to support several peer reviewed publications that have been important contributions to the field: Difficulties in daily living experienced by adolescents, transition aged youth, and adults with FASD; Suicidality and associated factors among individuals assessed for fetal alcohol spectrum disorder across the lifespan.

Dr. Cook shared some of the unpublished information in the database about individuals that self-identified as Indigenous. It is really important to understand the health and intervention needs of Indigenous individuals with FASD, both the vulnerabilities and the resiliency factors and these data can help us to understand their stories, needs and experiences, and to break down misinformation or stereotypes. By examining the data in this way, we may learn about the referral patterns and the service and health needs of all individuals who go through the FASD assessment process—those who receive a diagnosis of FASD, and those who do not receive a diagnosis of FASD but have prenatal alcohol exposure.

Data that is specific to ethnicity is very carefully managed by the National FASD Database oversight committee and has yet to be published. The committee requires that specific clinics that only see Indigenous individuals have a say in how or if the data will be used.

Key takeaways:

- The CanFASD National FASD Database has information that may assist in better understanding the health and social needs of Indigenous patients.

Care must be taken to appropriately and accurately interpret ethnicity-specific data about people who access FASD diagnostic services.

### **Webinar #3: Case examples of Culturally Safe practices by FASD diagnostic clinics**

**April 28, 2022, policy only**

Dr. Lori Vitale-Cox, Eastern Door Center in Elsipogtog (Elsi-book-took) First Nations in New Brunswick

*Dr. Lori Vitale Cox is a community researcher and clinician who works in Elsipogtog First Nation where she is the Director and founder of the Eastern Door Center for diagnosis, prevention and intervention of neurobehavioral disorders related to prenatal exposure to trauma, drugs and alcohol. The ED (eastern door) was the first centre for FASD in Atlantic Canada offering multi-disciplinary diagnosis. She served on the NB FASD advisory group that developed the proposal for the NB FASD Centre of Excellence. The ED model informed the development of the provincial centre. She was hired to help train and develop the provincial team during their first few years of operation. Lori works on many projects related to FASD in the Atlantic provinces and is a strong advocate for Indigenous groups leading their own work.*

Re-balancing the Wheel Elsipogtog Eastern Door Centre: Two-eyed seeing in the diagnosis, prevention and intervention of FASD and related conditions.

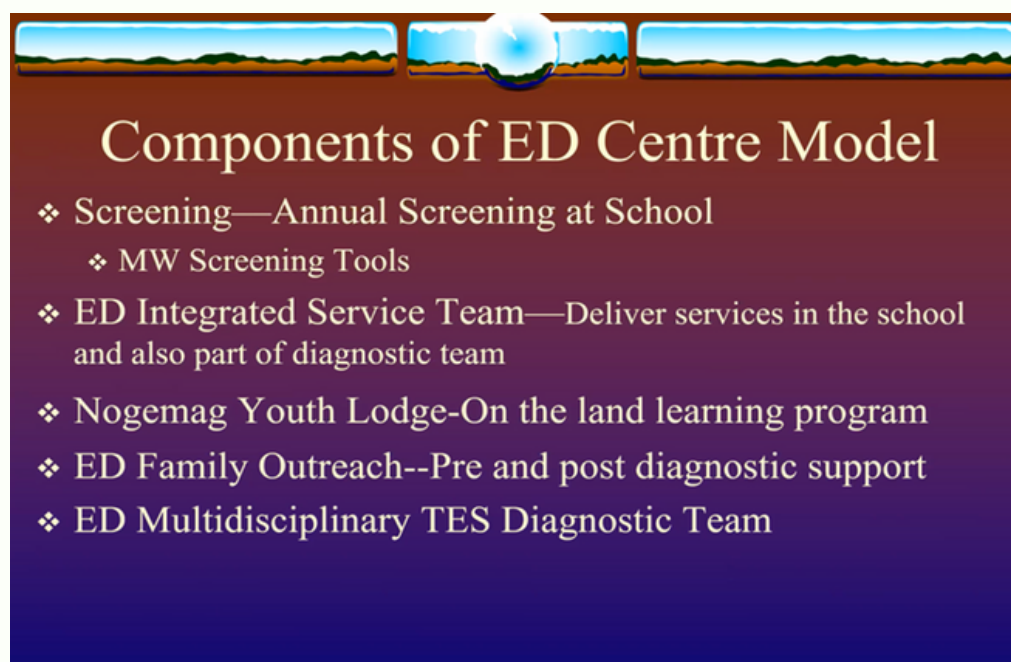
The Eastern Door clinic developed from a 1997 study that looked at the high suicide rates in the community and had identified learning disabilities and other un-met youth needs. From this a community-based action research project was commissioned by the Wellness Committee. The screening tool 'MW student teacher index' was used by classroom teachers to identify students having difficulties. This was followed by a semi structured interview with students' mothers, that collected their stories in their own words. The mothers were comfortable to describe the many layers of adversity and trauma – their child's and their own- because of the safe space that was created.



This included descriptions of relevant social determinants of health factors, and whether they experienced pregnancy exposure to alcohol and nicotine.

A collaboration between Indigenous and provincial health professionals was formed to begin onsite diagnostic clinics. They found many things in this process including many undiagnosed medical conditions (vision, hearing, nutritional), mental health issues, and a high prevalence of FASD -19.4%. Elsipogtog then developed a five-year strategic plan to address these findings which included additional school resources, a youth program on the land, expansion of the screening tool to be more cultural, and through this process developed the Eastern Door model for FASD diagnosis. They then expanded to prevention and intervention supports.

The current model includes:



This model has helped them to leverage many other services, partnerships and supports. They see FASD as 'System Disorder;' FASD manifests in an individual but affects the family system relationships and the larger social system in the context of the person's life. A community elder identified that FASD can be seen as disordering – a dysregulation of relationships, both internal and external.



Healing can be seen as a process of restoring and strengthening those relationships to rebalancing the medicine wheel- socially, emotionally, physically, and mentally.

In 2014-2015, Elsipogtog were able to show a reduction in FASD prevalence to 12.8% -14.5%. They have also increased the protective factors of early diagnosis, school, and home accommodations. There is also a reduction in stigma as the focus has been on culturally safe interventions, support pre- and post- diagnosis to improve success and family well-being. Stigma regarding FASD has diminished to the point that mothers are now referring their children to access the supports.

Jolene Harwood-Gramlich, Onion Lake Cree Nation, Maternal Health Program, Saskatchewan

Barb Martel, Onion Lake Cree Nation, Support worker, Saskatchewan  
*Jolene Gramlich is a Licensed Practical Nurse for the Onion Lake Health Centre's maternal child health team. Her role includes being coordinator for the Onion Lake FASD Diagnostic Team. She have been lucky enough to have been working for the health centre for the past 13 years. She recently pursued her passion for breastfeeding and became an International Board-Certified Lactation Consultant which she tries to do as much as possible when not coordinating the team. She has two young girls at home.*

Part of the health services that is offered to members of Onion Lake Cree Nation, identified that support and diagnosis was needed beyond the prenatal supports that they were being offered. They worked with other services in the community including education. They identified that they needed an FASD diagnostic service and sought out training on how to do this. They recognized how important the diagnosis can be to the child in order to improve understanding about their neurodevelopment, and increase access to services. The team includes a physician, neuropsychologist, speech language pathologist, clinic coordinator and FASD Support worker.

The Onion Lake FASD diagnostic team were worried about diagnosing children and not having enough support services, but realized that the diagnosis can help lead to more services- this was the case for them. They were able to apply for an FASD worker position.

Since 2012, they have completed 25 assessments and identified more to be assessed. This is not a full-time clinic but as cases come forward, the staff work with families to gather the information and bring the team together as needed.

Post clinic, the health centre provides an FASD outreach worker who helps families to follow through on the clinical team recommendations. As well as advocating for families' needs, FASD outreach workers also operate groups and cultural activities, help with homework, and help the families through the entire process (filling out paperwork, understanding the diagnosis, accessing services, etc).


Funding continues to be an issue. The coordinator position is funded through the health centre; the outreach worker is funded through Jordan's Principal. In the beginning, the Battleford Gold Eagle Casino was a donor for many years that paid for the assessments, but this funding has now been discontinued. The clinic is really struggling to find the money on a case-by-case basis; this really slows the process down and is not sustainable as it is so time consuming. Consistent funding would be so important and a priority to see a set number of kids in a year.

Wanda Beland, Executive Director, Northwest Regional FASD Network, High Level, Alberta

*Wanda Beland is the Executive Director of the NWR FASD Society based out of High Level, Alberta. This agency serves the Mackenzie Region, which covers the northern area of Alberta.*

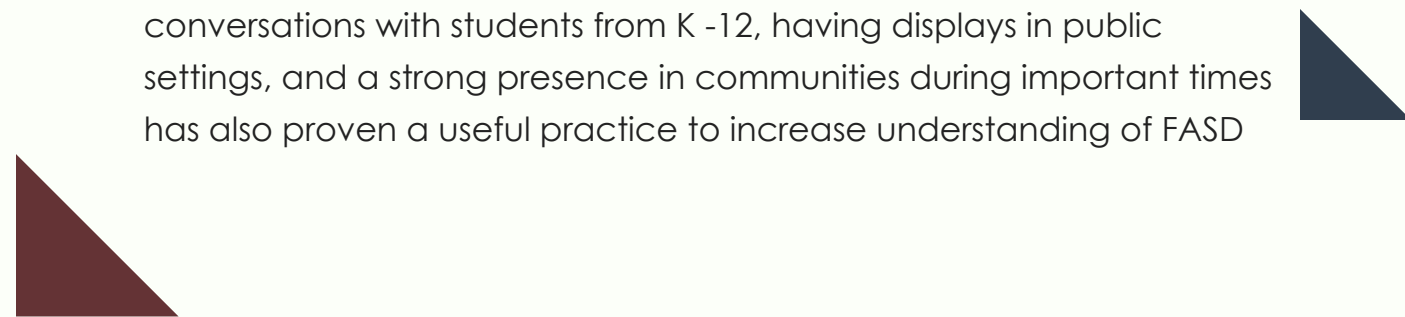
*Wanda has been involved in the society since 2004, as a volunteer, board member and in 2008, when the Mackenzie FASD Service Network was established, as the Executive Director. Wanda, along with her husband Marc, are adoptive parents of four adults with FASD. A teacher, she has a degree in education, and a Fetal Alcohol Spectrum Disorder Education certificate from Lethbridge College. She is the executive director of the NWR FASD Society; has coordinated diagnostic clinics, caregiver/family, youth and adult FASD programs and Parent-Child Assistance Programs (PCAP). She grew up in a traditional First Nations family in the north and brings remote and isolated area experience, especially from aboriginal areas and perspectives.*

In 1996 an FASD Committee was formed in the High Level, AB area that included First Nations, Métis Community, Justice departments, Health services, FNIHB, Education, parents/caregivers, Addiction, RCMP, and community members. From 1996-2003, they raised money to be able to offer more services and training. They recognized that for services to change their practice we needed to have people diagnosed. In 2002-2003 they were trained by Lakeland Centre for FASD on how to do diagnosis, and began to offer services in 2004. Funding became unsustainable in 2006, but Alberta was developing Primary Care Networks (PCN) in Health, and proposed that the High Level FASD diagnostic clinic become part of this network. This proposal was accepted to provide pediatric FASD diagnosis. In 2007 they expanded to include an adult FASD diagnostic clinic in collaboration with First Nation partners. Further funding came from the province as part of the FASD Service Networks and allowed further expansion of diagnosis and intervention services. Services have grown and reduced as priorities of the PCN have changed and other funds became available, including funds from First Nations Health.



Today, 24 youth and 12-16 adults are diagnosed per year. One lesson learned is the importance of creating and maintaining relationships. High Level has a diverse demographic, with four first Nations, Mennonite communities, towns, and a Métis Settlement. The work is done face to face so that a relationship with families and communities is developed. Building relationships with families accessing FASD diagnostic services means spending time getting to know the family- not moving immediately in to gathering information about alcohol use in pregnancy. The program focuses on removing barriers that families face accessing services, and ensuring families are comfortable with every part of the process, creating a 'pathway of least resistance.' In practice, this includes providing transportation for families, ensuring that they get the services that they need; providing pre-clinic, clinic day and post-clinic supports to the families; creating the pathway of least resistance to services; connecting with extended family; and participating in communities beyond clinics.

Some barriers were initially experienced but have been overcome such as the worry about labelling; stigma; a feeling of First Nations focus only, programs that are not sustainable; travel; historical and generational trauma; no physical presence in communities; lack of internet and phone services. Many conversations with community members, leaders, and schools helped the community to understand the benefits of the diagnosis, as a means to supports and services. An increased understanding of FASD helped to avoid negative labels associated with the diagnosis, and to ensure the community understood that FASD is not a First Nations or cultural issue, it is an issue related to alcohol use that exists throughout the world. Sometimes misconceptions about this still need to be corrected through frequent conversations. The clinic has connections to an Elder, whose direction has been very helpful. Having conversations with students from K -12, having displays in public settings, and a strong presence in communities during important times has also proven a useful practice to increase understanding of FASD



and the organization's process. The clinic focuses on ensuring their actions show they are not stigmatizing or labelling people with FASD- stigma reduction is not just about what we say, it's about what we do. Post clinic supports can include referral to several inagency programs, completion of forms, follow-up with families, updating assessments at transition times, checking in on a regular basis with individuals/families, and providing FASD support workers that are community specific. One specific task that families are supported in is how to talk to children/youth who receive a diagnosis- support workers tell parents, 'how you speak about your child's diagnosis is up to you,' returning power to families to shape the narrative about FASD. Some times, the term 'FASD' is avoided, as it not always perceived as a culturally safe term. The clinic supports circles to discuss the FASD diagnosis, ensuring the information about prenatal alcohol exposure is only one part of the discussion. The clinic focuses on discussing the functional abilities and strengths of the person with FASD. There is no timeline on how long individuals can be involved post clinic. The organization is intentional about hiring individuals as staff from the various communities.

Key takeaways:

- Talk with and involve the community
- Take the time to have difficult conversations
- Make sure the diagnosis is directly linked to interventions
- Address the social determinants of health
- Consistent and sustainable funding for dx and ongoing supports
- Training and Mentorship from a seasoned clinic is helpful to new clinics
- In community partnerships and building relationships
- FASD is not a label or identity but a diagnosis
- Sharing the strengths of individuals

"Power of a community to find what is needed and to come up with the solutions." Dr. Lori Cox

**Webinar #4: Respectful engagement with Indigenous Communities:  
A conversation to explore culturally safe practices for FASD diagnostic  
clinics.**

**June 23, 2022, policy only**

*Dr. Melissa Tremblay is a member of the Métis Nation of Alberta and was born and raised in rural Alberta. Melissa is a Registered Psychologist in the province of Alberta, and an Assistant Professor in both the School and Clinical Child Psychology Program and the Counselling Psychology Program at the University of Alberta. As the mother of three young children, Melissa is acutely aware of the need to strengthen opportunities for Indigenous children and youth to deepen understandings of their cultures and histories. With her earliest frontline work in the area of forensic counselling, Melissa has a long-standing interest in walking alongside structurally marginalized young people on their journeys toward health and wellness. Her research work takes a relational, community-based participatory approach and has allowed her the privilege of working in partnership with Indigenous peoples, communities, schools, and agencies across the country. Melissa's work also maintains a strong focus on advocating for transformative, community-grounded approaches to supporting Indigenous children, youth, and families to access their strengths and wisdom.*

The objectives of the presentation were 1) to expand understanding of what it means to provide culturally safe FASD diagnostic services; and 2) to deepen understanding of Indigenous worldviews as relevant to FASD diagnostic process.

Cultural Awareness	An attitude that includes awareness about differences between cultures
Cultural Sensitivity	An attitude that recognizes the difference between cultures and that these differences are important to acknowledge in health care
Cultural Competency	An approach that focuses on practitioners' attaining skills, knowledge, and attitudes to work in more effective and respectful ways with Indigenous patients and people of different cultures
Cultural Humility	An approach to health care based on humble acknowledgement of onset learner when it comes to understanding a person's experience. A life long process of learning and being self-reflective.
Cultural Safety	An approach that considers how social and historical contexts, as structural and interpersonal power imbalances, shape health and health care experiences. Practitioners are self-reflective/self-aware with regards to the position of power and the impact of this role in relation to patients. "Safety" defined by those who receive the service, not those who provide it.

Churchill, M., Parent-Bergerson, M. Smylie, J., Ward, C., Fridkin, A., Smylie, D., & Firestone, M. (2017). Evidence Brief; Wise Practices for Indigenous-specific Cultural Safety Training Programs. Retrieved from [222.welllivinghouse.com](https://222.welllivinghouse.com)



It is important to address the health disparities experienced by Indigenous peoples and acknowledge the historical and ongoing colonization. This space can cause discomfort; however, it can be a powerful learning tool. This is a part of cultural safety.

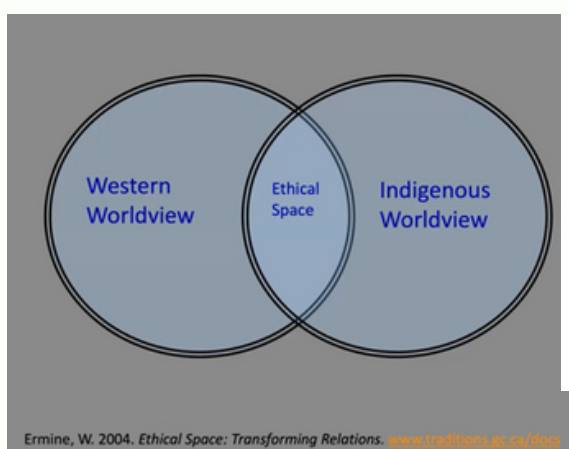
Colonialism is a part of Canada's history, such as residential schools, but it is also a current event that continues to occur in systems. It has been argued that the current child welfare system is a continuation of the residential school system with the injustices occurring to Indigenous children. The Missing and Murdered Indigenous girls and women is another ongoing and current manifestation of colonialism. Colonialism includes loss of self-determination, unbalanced power, loss of traditional knowledge, profound intergenerational trauma and violence.

The group was asked: how have FASD diagnostic services contributed to colonialism? Discussion by the group included:

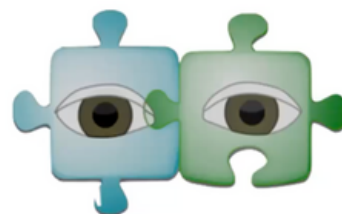
- some indigenous perspectives have raised that the term FASD is systemically racist
- a government operated FASD diagnostic clinic can be uncomfortable/create barriers for people and can have a power dynamic; even though efforts are made to make it open, it is a one-way process. How do we make these processes less one way when we are bound by organizational policies?
- issues of stigma exist for people who receive the diagnosis
- In some cases, protective thinking by professionals about stigma may lead them to hesitate to give an FASD diagnosis to Indigenous patients, but this could be seen as paternalistic, and a diagnosis that is free from stigma should be a right to everyone.
- Discomfort from these processes comes with colonial baggage

### Moving forward with culturally safe FASD diagnostic services

Dr. Tremblay described the idea of cultural safety as a process – we are always learning. We might learn a successful tool or project with one group, but this may not work as well with another group. It is an ongoing process of learning, adapting, being sensitive to the background and diversity/experiences of social issues. Cultural safety is context dependent, and should be approached as considerations rather than a checkbox.



### Two-eyed Seeing



Bartlett, Hatcher, Marshall, & Marshall 2007

Western and Indigenous worldviews can come together in collaboration – history, traditions, values and where we come from can significantly affect how we communicate and think about one another. An ethical space is a different space where different cultures and knowledge systems can come together to create synergy.

The concept of two-eyed seeing – learning to see from one eye the strength of Indigenous knowledge and ways of knowing and from the other eye the strength of western knowledge and ways of knowing; and learning to use both eyes together for mutual benefit.

These concepts require intention and ongoing of journey of co-learning to develop the collaborative understanding. Not just these words or romanticizing these concepts, these concepts require a commitment that is ongoing.

These concepts align with participatory approaches, although this slide focuses on research it can be applied to any engagement with communities.

## Participatory approaches



Working with Indigenous communities needs to be more on the engaged and participatory side of this spectrum. Participatory can have various levels of involvement, for example diagnostic clinics can be community driven, Indigenous-led, or more in the middle of community based. There is not one solution for every community, but wherever services fall on the spectrum, these decisions of what kind of services are appropriate should be made in collaboration. The collaborative approach can be empowering for the community to take ownership and pride in the services.

### Reshaping the narrative

- Taking a critical lens to colonial story
  - Deficit-focused, problem centered, reactive
  - Pathologizing the individual
- Stories of strength and resilience – generational strengths and wisdom

- Trauma wisdom (Turcotte, 2014) – from trauma and hardship can bring us wisdom, learning and wiser.

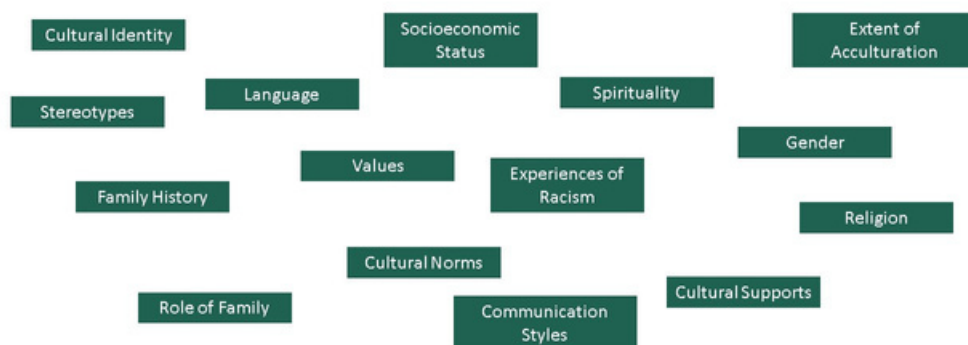
Many communities have the wisdom to address prevention, intervention and diagnosis of FASD.

Taking a holistic approach to look at the whole person to address emotion, spiritual, physical, mental – this can be transformative for diagnostic services to recognize that we cannot separate out different aspects of health. Health is deeply tied to spirit. Living in balance. Some questions that diagnostic services can ask include:

- Do people in this community have access to traditional ceremonies? What is your experience when you do participate in traditional ceremonies?
- What is your traditional language?
- To what extent do you relate to your cultural heritage?
- What is your knowledge of your history and how this informs how you are in the world?
- What kind of medicines do you have and what medicines are available in this community – herbs, beading, hunting, etc?

All of these are relevant to FASD diagnostic services and clinicians should be aware and trained to look at this holistic picture, not the technical criteria. How can we more holistically view this person so that we can help to shape services.

### Case Conceptualization



Relationship is important to consider in many aspects:

- Relationship with the natural world – relationship with the streams, hills, grass, trees that are not understood in the western world
- Relationship with Ancestors – relationships that are active with those that have passed from this world. Being diagnosed with depression may mean an ancestor is trying to communicate something and treatment would involve understanding what that ancestor is trying to say.
- Balance within relationships
- Relationships within a whole person

We can practice reflexivity of service providers and diagnostic services by exploring our:

- Assumptions
- Colonialism
- Moving beyond acceptance
- Reflecting on our knowledge
- Racism and discrimination

People need to know that their cultural and ways of knowing are respected.

#### Accountability

- More research on the information on diagnostic services' effectiveness with Indigenous people would be beneficial.
- Accountable to individual and communities
- Doing our own work as clinicians – learning about history, about local cultures, language, traditions
- Moving beyond good intentions

#### Resources:

Working with Indigenous Populations and Communities: A guide to culturally safe practice and humility. Nov 2021. Practice Guideline – Canadian Psychological Association,

Psychology's Response to the Truth and Reconciliation Commission of Canada Report. A report of the Canadian Psychological Association and the Psychology Foundation of Canada.

### **Overall Key Considerations from this Series**

This series of presentations was developed and delivered to policymakers to help government departments understand the uniqueness of the FASD diagnostic process, the purpose and importance of timely diagnosis, challenges and strengths for consideration in the development and delivery of culturally relevant FASD diagnostic services. The following is a summary of the key considerations, based on the evidence and experience of CanFASD and its stakeholders:

1. There needs to be a greater understanding of FASD and FASD diagnosis across government, including the importance of diagnosis as it relates to better outcomes.
2. FASD diagnostic clinics in Canada have been resilient and creative, however, in order to be sustainable, stable supports including funding are critical,
3. Multi-disciplinary teams are imperative for effective FASD diagnosis and to identify and engage appropriate support services.
4. Canadian FASD diagnostic clinics are more successful when they adapt to the community/regional needs
5. Multi-disciplinary FASD diagnostic teams need to be connected to, and understand the community they serve.
6. New FASD diagnostic services need training and mentorship
7. Relationships between FASD diagnostic clinics and community stakeholders is critical.
8. Indigenous communities should be involved in FASD diagnostic service development and delivery.
9. FASD diagnosis needs to be linked to support or intervention services as these links greatly improve outcomes for people with FASD, their families and support systems. FASD diagnosis can also provide information to support the need for these supports and /or intervention services.

10. The CanFASD National FASD Database has information that may assist in better understanding the health and social needs of Indigenous patients.

### **Implications for Policy**

Several policy recommendations emerged from this webinar series, which would support the continued enhancement of culturally safe and trauma-informed approaches to assessment and diagnosis practices:

- Develop and implement funding mechanisms that can be accessed by community groups to establish diagnostic clinics, including recommendations and standards for training and mentorship.
- Develop a guide that outlines considerations for culturally relevant and community engagement with communities for the development or use of FASD diagnostic services.
- Identify funding to explore the Indigenous-specific research in the National FASD Database to determine the unique health and social needs of this population.
- Consider collecting information for Indigenous families about their experiences with FASD diagnostic services and how they can be improved, sharing this information with the diagnostic clinics for improvement.
- Consider asking FASD diagnostic clinics how the increased capacity for service might be achieved.
- Developing dialogue with other government departments that may have the capacity to develop and deliver FASD diagnostic services such as youth and adult corrections, education, forensics, mental health facilities and child welfare.

For more information about the CanFASD Research Network and FASD, please visit [canfasd.ca](http://canfasd.ca).