THE NATIONAL FASD DATABASE

NEWSLETTER

Fall Newsletter / November 2021

PROJECT UPDATE

- 3,664 records as of November 3rd, 2021
- WELCOME to two new clinics: Glenrose Rehabilitation Hospital Child and Adolescent clinic AND Adult clinic!
- There are now 29 clinics contributing data
- THREE additional clinics are almost ready to start contributing their data!
- The project team has been working hard to expand the database, including a recent grant submission to CIHR (see page 4)
- Dr. Cook and Audrey McFarlane recently presented to the Deputy Ministers of the Canada Northwest FASD Partnership on the National FASD Database

DATA HIGHLIGHTS

- 96.7% of clients have confirmed PAE
- 63.5% of clients have FASD (8.9% with SFF), 10.6% are designated as At Risk, and 25.9% do not have FASD
- 43.8% of those with FASD have an IQ less than 70, while 5.7% and 8.1% of the At Risk and No FASD groups have an IQ less than 70, respectively
- 8.5% of individuals with FASD had growth restrictions while 3.1% and 4.0% of the At Risk and No FASD groups had growth restrictions
- The three most common substances currently being used by individuals with FASD were: Marijuana (21.7%), Alcohol (21.0%) and Tobacco (14.5%)
Digging even Deeper into the Data!

For the first time, we have been able to examine the data by sex. Below are just some of the findings specific to those diagnosed with FASD.
Database Publication Summary


**Summary:** There is growing evidence that suicidal ideation, attempts, and death occur at high rates among individuals with PAE/FASD. A sample of 796 records from the National FASD Database was analyzed to explore the relationship between suicidality and numerous demographic and biopsychosocial factors. These are just some of the important findings published by Flannigan et al. (2021):

Across the whole sample, 26% of participants were reported to have past or present suicidality.

A more detailed analysis revealed that some challenges and experiences are associated with higher likelihood of suicidality:

- Current substance use
  - 6.7x increase
- Experiencing trauma/abuse
  - 2.8x increase
- Affect regulation impairment
  - 1.9x increase

Individuals with PAE/FASD who have the following challenges were more likely to experience suicidality than those without these challenges:

- Anxiety or depressive disorders
- PTSD or adjustment disorders
- Living in group care or institutional settings
- Legal problems with offending

*The article will be free to access. The article will be found on The Canadian Journal of Psychiatry [website](#) and shared in TEAMS.*
**FOCUS ON RESEARCH PROJECTS USING DATAFORM**

**Update on the Client-Oriented Mapping for Point of Care Access to Supports and Services (COMPASS) Project**

*Dr. Jocelynn Cook, Dr. Jacqueline Pei, Dr. Kaitlyn McLachlan, Kathy Unsworth*

To date, researchers have used the National FASD Database to analyze neurodevelopmental patterns across varying developmental periods. The next step is to link this evidence to generate client specific recommendations that support success throughout the lifespan. To date, the research team has been able to identify classes of individuals with PAE according to their neurodevelopmental functioning; characterize differences for each class on individual/contextual and clinical factors; and evaluate patterns of recommended interventions and supports for each class in the context of functioning and needs. With an understanding of common recommendations made based on a client’s functioning and needs, the team has started to align the evidence with the *Towards Healthy Outcomes Model.*

Next steps: The team will begin to develop COMPASS materials, including the development of an “algorithm” to generate individualized recommendations and reports based on client characteristics. Shortly, the team will be working with clinic partners to pilot and finalize the tool along with seeking feedback on the proposed plan for how the tool can be used by clinics.

---

**GRANT PROPOSAL SUBMITTED!**

In September, Dr. Cook and colleagues submitted a grant proposal to the Canadian Institutes of Health Research. Using the database, the project will examine potential correlates of risky/problematic alcohol use among youth, particularly in adolescent girls and women with PAE. The project will also seek to develop new items for the database, focused on strengths and protective factors of youth with PAE that contribute to resiliency against adverse experiences.

Results of this funding opportunity will be released late February of 2022!

---

**FALL & WINTER LEARNING!**

**COURSE ALERT:** Two CanFASD online courses will be updated this fall: Prevention Conversation and FASD for School Staff Level II. A significant change to the Prevention Conversation course is the adaptation for use with Indigenous communities.

We are also excited to announce that a new course is in the works, which CanFASD hopes to launch in the new year: FASD for Community and Social Services Professionals Level II. Watch for an announcement on the course updates and new course release!

---

**A FOCUS ON CAREGIVERS – RESEARCH OPPORTUNITY**

**Exploring the Experiences and Perspectives of Caregivers of Individuals with FASD**

*Dr. Jacqueline Pei, Dr. Katherine Flannigan, Ms. Dorothy Reid, and Ms. Audrey McFarlane*

FASD is a complex disability. Caring for someone who has FASD comes with unique challenges and successes. Unfortunately, there has not been much research to understand the whole experience of caring for someone with FASD across the lifespan. Therefore, we would like to learn about the lived experiences of caring for someone with FASD across the lifespan.

Please consider supporting this project by bringing it to the attention of caregivers of individuals with FASD. Full study details can be found following the link below and a printable ad that you can share and post in your office is found on the last page of the newsletter.

[https://redcap.ualberta.ca/surveys/?s=YCN8XAEPCH4RWCX](https://redcap.ualberta.ca/surveys/?s=YCN8XAEPCH4RWCX)
Getting to know our clinics!
Featuring FASD Okanagan Valley Assessment and Support Society: An interview with Bernadette O’Donnell

Tell us a little bit about your clinic. How many staff do you have? How many diagnoses do you do a year? How long have you been in operation?

Our clinic boasts of a “Dream Team” of two “Super Women” …a director, Bernadette O’Donnell and a social worker, Kim O’Neill and our amazing assessment team includes: a physician, a neuro psych and an OT. Last year we completed 15 assessments. We are the only clinic in BC who focuses on assessing adults; those involved in the justice system, and those incarcerated. We stay with our clients after their diagnosis to ensure they are connected with community supports and accessing government supports. We offer 1:1 support, as well as weekly support groups: adult, teen, Indigenous and caregiver. We also offer Wel-briety for those healing from addictions and trauma. We host 40 clients/week for support. We also do workshops across the province and last year spoke to 860 people provincially as well as internationally. We’ve been running for 6yrs.

How is data helping you with your work?

Data helps us to better understand how FASD is playing out in our client’s world – the barriers, the interventions and supports needed to change their trajectory. It helps inform us and our community about the deeper questions and see the patterns that help us focus on best practice. Even our own data continually provides us with evidence of needs and successful outcomes. We collect our own data because there is more to learn about adults with FASD. We are seeing health patterns that cause us to reach out to researchers and connect with them around the world in order to ensure an increased understanding of how FASD is impacting the body of our clients. With new knowledge, we are able to approach experts to resolve issues.

What is the biggest lesson that you have learned in your work?

Some days, we think we know about FASD, but, in fact, we know so little. Everyday we are reminded by our clients about what it is like for them to communicate and move freely (or not so freely) when you have FASD. Everyday, how difficult it is to feel included in a community that does not know FASD in year “2021”. We have learned to be tenacious advocates while educating others about FASD... never to assume people know what you are talking about, or how to support our client, even when they say they know about FASD. Assume they do not know anything that has been learned since 1980! Carry the torch high, our adults need and want the: education, health, justice, recreation, housing, addiction communities to give them time and regard. With adequate supports, they are capable of so much.

What has been your greatest achievement and your proudest moment?

Our greatest achievement is giving second chances to adults over 19 to see themselves as “not losers!”; hearing them say, “You mean I don’t have to live like this anymore!” At long last, after 20+ years, giving them vision when they had triple vision; giving them access to professionals and medications giving them control over their anger, their seizures, their depression. Resolve their dentistry issues which lowered their brain inflammation so they could function without pain; to get their children back; to have the experience of giving and receiving a hug from a family member; to resolve their addiction issue; to face a judge and receive sentencing that does not involve incarceration. Knowing lives were saved (literally) by the work we do is our greatest achievement.

Our biggest protest moment is accessing funding to complete adult assessments and operate our clinic. Our province provides NO access to assessment funds when you are over 19.
Getting to know our clinics!
Featuring FASD Okanagan Valley Assessment and Support Society: An interview with Bernadette O’Donnell

What has been your biggest challenge as a clinic?
More professional medical personnel, than I ever thought possible, people who make decisions that directly impact our clients, have so little information and truth about FASD. – as one gynecologist responded when asked why she did not have pamphlets about FASD in her office, “Oh, we only deal with pregnancy here.” Another told a client he could not have FASD because “your mother only drank in the first trimester”. How can we get the College of Physicians to address this large lack of education? We have come so far but there is a whole generation who needs information.

What is something new and exciting going on at your clinic?
We are working with BC Housing, Fraser Health, Community Living BC to provide service delivery to a home for women with FASD and active addictions. There is always hope that governments will see the massive need for adult supports and mental health care for those with FASD.

Updates

Database in the literature
Dr. Jocelynn Cook, Dr. Katherine Flannigan, and Ms. Kathy Unsworth recently published an article in *BMJ Open* that describes the protocol of the National FASD Database study. The article provides a brief, yet thorough, overview of FASD, the impetus and development of the database, and the collaborations which resulted in the data fields included in the Database.

The primary research questions that guide the use and analysis of the Database are presented and the methods by which these research questions will or have been addressed are described.

Recent Database Articles and CanFASD Issue Paper


CONGRATULATIONS

Congratulations to Northwest Peace FASD Network in Grand Prairie, AB as they entered the 3,500th record into the National Database!

Congratulations to Manitoba Centre, NEO Kids FASD Diagnostic Clinic, and New Brunswick FASD Centre of Excellence for having the top three most complete datasets in the Database!