CanFASD
CANADA FASD RESEARCH NETWORK

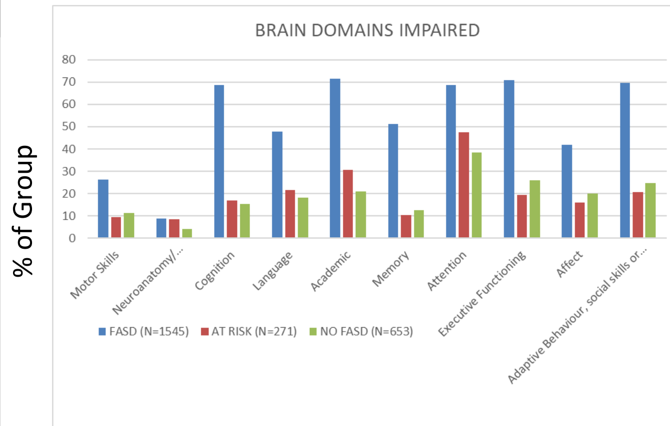
THE NATIONAL FASD DATABASE

NEWSLETTER

Spring Newsletter | April 2021

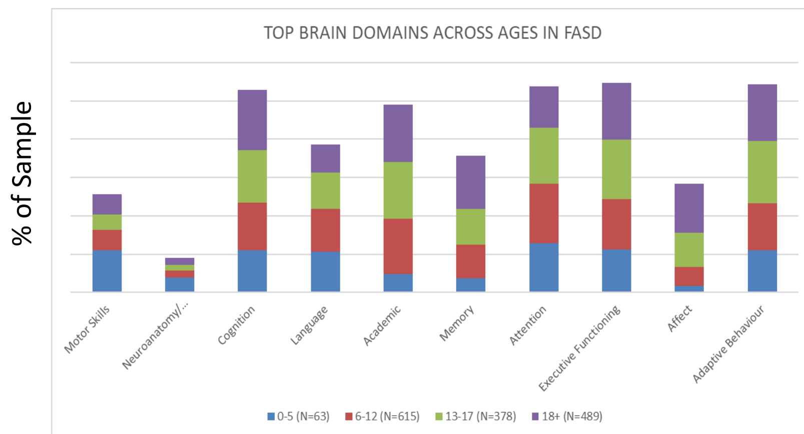
PROJECT UPDATE

- 3,379 records as of April 26, 2021
- WELCOME to our new clinic participant: Regina Qu'Appelle Health Region Child and Youth Services: Cognitive Disabilities Program!
- SIX additional clinics are almost ready to start contributing their data!
- The project team has been working hard to expand the data analysis
- Project COMPASS is now underway, using National database data to guide interventions
- A project on suicide will help us to better understand suicidality among those with FASD
- J. Cook is working with researchers in the USA, the UK, and Australia to define common measures for defining FASD for research purposes



DATA HIGHLIGHTS

- 92% of the records have confirmed PAE
- 62% have FASD (9% with sentinel facial features), 11% are At Risk and 27% do not have FASD.
- 37% of all records were exposed only to alcohol in utero; 63% were also exposed to other substances
- Among those with FASD, 43% were also exposed to nicotine, 29% to marijuana and 18% to cocaine/crack.
- Those with FASD had significantly more brain impairment, physical and mental health issues than those At Risk or without FASD.
- More than half of those with FASD in all age groups had significant impairments in the Cognition, Attention, Executive Function and Adaptive Behavior, Social Skills or Social Communication domains.



RESEARCH TEAM

Dr. Jocelynn Cook
PhD, MBA
Principal Investigator

Ms. Kathy Unsworth,
MHSc, MBA
Program Manager

Mr. Andrew Wrath
BA (Hons.)
Research Assistant

SUMMER LEARNING!

NEW <u>FREE</u> COURSE ALERT: CanFASD has opened the Identifying Best Practices for FASD online course for registration. It is free to everyone for the first year. https://canfasd.ca/online-learners/

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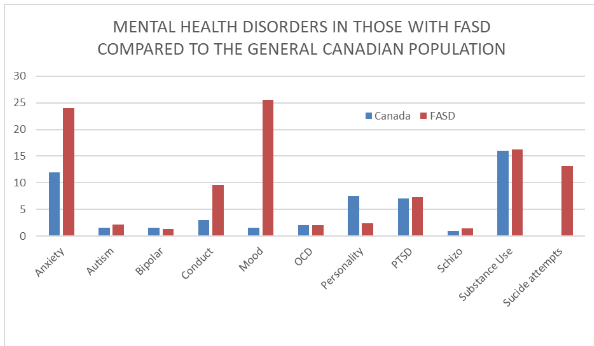
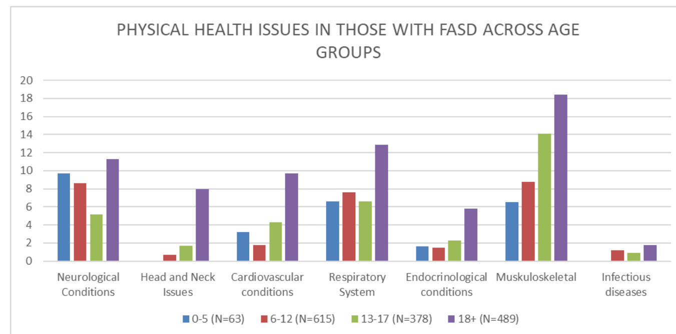
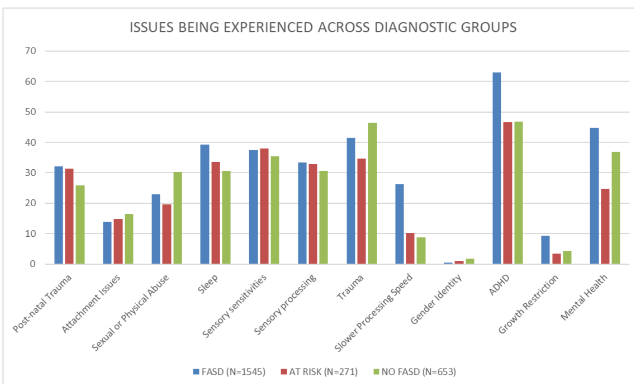
Digging even Deeper into the Data!

We are learning more and more about the brains, bodies and experiences of individuals with FASD in Canada…..





- Adolescents/adults with FASD are 14 times as likely to have Anxiety than other Canadians
- They are 4 times as likely to have a mood disorder and 6 times more likely to have a substance use disorder
- 20% of adolescents and adults have suicide attempts/ideation, which is 2,000 times more than their non FASD counterparts
- Individuals with FASD and without FASD in the National Database tended to be similar in other issues, except those with FASD had increased rates of ADHD. This could be due to the nature of the population: similar in prenatal exposure to alcohol as well as other prenatal exposures.



More research questions….

- Are there sex differences for brain domains impaired, mental health or physical health issues with FASD?
- Are adolescents/adults with FASD more likely to be using cannabis if they have a mental health issue?
- Does IQ score across age groups correlate with specific brain domains?

If you have a research question, please let us know!

Database in the Literature

Comparing outcomes of children and youth with fetal alcohol spectrum disorder (FASD) in the child welfare system to those in other living situations in Canada: Results from the Canadian National FASD Database

A total of 665 youth and adolescents with a clinical diagnosis of FASD under the age of 18 living in child welfare care, with biological, adoptive or other family members, were included in the sample. Results revealed a significantly higher rate of reported sexual and physical abuse among individuals in child welfare care compared with those living with biological parents or with adoptive or other family member(s). Rates of difficulty with the law were also higher among those in child welfare care compared with adoptive/other family members. Conversely, the rate of mood disorders was significantly higher among those living with adoptive/other family members compared with child welfare care. Similar rates of reported suicidal ideation/attempts across all living situations, as well as mental health concerns were reported.

More Data Snaps:

- 27% of those with FASD had a sibling with FASD and 7% had a parent who was diagnosed
- Those with FASD who had also been exposed to cannabis had ADHD more often (70% vs 57%). So did those who had also been exposed to opioids prenatally (70% vs 57%).
- Individuals with FASD who met criteria for growth restriction were twice as likely to have a mood disorder when compared to those with normal growth parameters.

FOCUS ON RESEARCH PROJECTS USING DATAFORM

Two new projects have been funded to CanFASD Research teams using the National Database! Congratulations to all! Here are the highlights...

SUICIDALITY AND RELATED RISK FACTORS AMONG INDIVIDUALS ASSESSED FOR FETAL ALCOHOL SPECTRUM DISORDER IN CANADA

Kelly Harding, Dorothy Badry, and Carly McMorris

This project is a partnership between the University of Calgary, CanFASD, and CASA Child Adolescent and Family Mental Health

(PolicyWise - January 2020 to September 2021)

Individuals with prenatal alcohol exposure (PAE) and Fetal Alcohol Spectrum Disorder (FASD) experience significant mental health concerns, including suicidality. Despite the high rates of suicidality documented within this population, the spectrum of this issue remains under-investigated in Canada. The aim of the current study was to ascertain: 1. the prevalence of suicidality among individuals assessed for FASD in Canada; 2. the demographic profile of individuals in Canada assessed for FASD who experience suicidality; and 3. the demographic factors that may increase the risk for suicidality among these individuals.

Among a study sample of 938 individuals assessed for FASD in Canada, we found an overall endorsement of suicidality of 22.5%, with individuals in adolescence (34.4%), transition-aged youth (34.1%), and those living in systems-based placements (51.3%) demonstrating markedly higher risk. Individuals diagnosed with FASD also experienced significantly higher rates of suicidality (26.5%) compared to those without a diagnosis (13.7%). Group differences were also explored by a number of biopsychosocial risk factors, including neurodevelopmental impairment, mental health and substance use challenges, other associated features (e.g., sleep, trauma), and adverse outcomes. The high prevalence rate found in this study is similar to findings published in other recent studies, both in the United States and Germany. These findings speak to the urgent need for screening, early identification of risk factors, timely intervention, and broad suicide prevention initiatives across the lifespan for individuals with PAE and FASD.

USING THE FASD NATIONAL DATABASE AS A COMPASS FOR FAMILIES

Jocelynn L. Cook, Jacqueline Pei, Kaitlyn McLachlan, Kathy L. Unsworth

(Kids Brain Health – September 2020 – September 2021)

A unique aspect of the FASD National Database is its capture of diagnostic, medical, mental-health, referral and behavioural data as well as recommendations for supports, services and interventions.

It is common for the number of recommendations to exceed 5, irrespective of age and diagnosis, and although a critical component of the assessment process they can be buried in lengthy clinic reports and are provided at a time when individuals and families are feeling overwhelmed.

The **goal** of this project is to move the Database outputs into a new phase of implementation that addresses this barrier. We will do this through the development of individual client-level evidence-based feedback tools, accompanied by intervention/support materials for use by FASD Clinics.

By linking individualized Database data to a lifespan evidence-based intervention model (Towards Healthy Outcomes), we plan to support clinics in producing systematic feedback reports, generated as knowledge and planning tools, designed to facilitate a shared understanding of intervention goals, increase consistency and intentionality, establish shared language, reflect shared philosophy, and open conversations with clients and families to generate a point-of-care context- tool.

In essence, a 'COMPASS' (**C**lient-**O**riented **M**apping for **P**oint of **C**are **A**ccess to **S**upports and **S**ervices) will be generated using the algorithms to map onto the Towards Healthy Outcomes framework, for recommendations that are strength-based, client-empowering, and goal-oriented, as well as tools and resources (e.g. info graphics, successful strategies and common considerations) for distribution by clinics to families. Recommendations will be accompanied by an explanation, which members of the support team can refer to.

Stay tuned for project results!

As always, we are thankful and appreciative of all that you do to support the National FASD Database and individuals and families across Canada. Here's to hoping 2021 brings us a year of less COVID and more tools, resources and services for individuals with FASD, their health and service providers and their families.

Getting to know our clinics!

Featuring NorWest Community Health Centre: An interview with Maureen Parks

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 includes two physicians; two Nurse Practitioners; one clinic coordinator; one FASD support worker (Part time); one Behavioural therapist; one Speech/language pathologist; one Occupational Therapist; 3 neuropsychologists that are connected to our clinic but work in private practice, and outreach workers. I hope I didn't forget anyone! The FASD program started in May 2002 but the assessment and diagnostic program started about three years later. Presently, we hold monthly diagnostic clinics and see about 6 people per clinic, totaling approximately 72 per year.

How is data helping you with your work?

Clinic reports and updates on recent research related to diagnosis and symptoms of FASD inform our clinic. We are able to observe trends in our patients' characteristics and features over time, which, in turn, informs our clinic operations and attention to specific and frequently impaired brain domains and adverse outcomes in our North Western population. Seeing frequent recommendations given to our clients also gives us a sense of what community supports may need to increase availability of services due to high volumes of referrals, which won't just come from our clinic.

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

My clients are the most awesome people in the world. Although they face challenges, their gifts are enormous. So many of my clients have amazing artistic ability; are musically talented; are gregarious; have great speaking skills; are accepting, caring and appreciative. I have learned that despite the barriers they may face they don't give up and that has taught me the importance of strength and resilience. I have learned there is no room for judgement. I have learned we must ensure there is always compassion, inclusion and opportunity for the clients we serve.

What has been your greatest achievement and your proudest moment?

When I think back to how this program started – the local parent group approached our CEO at that time to consider investigating the need for services for individuals that were alcohol exposed. NorWest secured a three-year grant and it took less that 6 months to realize the desperate need for individual support and diagnostic services. With that realization and the innovate and progressive nature of our community Health Centre we never looked back. I was allowed the opportunity to develop this program to where we are today. ***We still have so much work to do*, *so much more learning to do***. The needs of our clients are always at the forefront of what we do and we have many partnerships in our community that are helping us with meeting our clients' needs.

What has been your biggest challenge as a clinic?

There have been a few large challenges we have had and continue to face. The first is trying to keep the community engaged and have FASD remain on their radar. Even with such a large clinical team, we are doing our best to ensure that assessments are done in a timely manner. Providing diagnostic services to those who live in remote or distant communities comes with many inherent challenges (e.g., ability to even get to the clinic), but ZOOM has been helpful with this over the past year.

Tell us something that you do as a team that has been helpful during COVID.

We have been seeing clients via ZOOM!!! That has been working out well.

If you would like to answer some questions or share a story about your clinic in the October Newsletter please contact Andrew at andrew.wrath@canfasd.ca or send him a direct message on TEAMS.