# The National FASD Database

## 2019 Annual Report

CanFASD
CANADA FASD RESEARCH NETWORK

## The Need for FASD-Related Diagnostic Data

Recognizing that FASD is Canada's most prevalent neurodevelopmental disorder, the primary goals of this project are to further understanding of the implications of prenatal alcohol exposure through diagnosis and data which can be used ultimately to improve health and social outcomes for individuals and families that are affected by FASD. Data may be used to influence decisions related to behaviour, environment and social context at individual, family, community, regional, provincial and federal levels.

Early diagnosis of FASD and the identification of appropriate interventions can help mitigate the onset and/or severity of adverse health and psychosocial outcomes, while also eliminating a number of direct costs. Furthermore, accurate diagnosis provides a mechanism for entry into intervention and support services, resulting in a higher return on investment for health systems and programs.

FASD is both an **etiologic diagnosis** (i.e. identifying the cause) and a **functional diagnosis** (i.e. identifying consequences and needs). Receiving a diagnosis of FASD may assist with access to health, education, and vocational services tailored to the unique needs of FASD. The diagnosis of FASD may also help to identify women struggling with problematic alcohol use and present an opportunity to offer meaningful support.

There are a large number of comorbidities (e.g., mental health, attention deficit hyperactivity disorder (ADHD), memory disorder, executive functioning disorder, social communication disorder, motor planning disorder, etc), associated with FASD. That said, there is a paucity of information about the frequency of each co-occurring disorder or the common clusters of functional disorders in the Canadian population. Similarly, diagnostic clinics may make many treatment recommendations at the end of the FASD assessment process for health, mental health, social services, education, and others, but there is very little published work that informs the ability to make meaningful interpretations of the diagnoses and disorders, as well as to make recommendations for the most effective interventions.

## The Universal FASDataform Project: The Evolution

In 2005, the Canada FASD Research Network established an FASD Diagnostic Action Team to focus on increased diagnostic capacity. In particular, the group recognized the need for consistency and comprehension in diagnoses and diagnostic data across Canada so that data could be analyzed to clearly document the common problems – and recommended treatments – associated with FASD. This would provide the foundation for the first clinical dataset for FASD that would allow identification of trends and modalities related to prevention, prevalence and diagnosis of FASD.

Many previous attempts by FASD researchers to compare data across multiple prospective and retrospective human studies failed because of differences in the collected data and difficulty in coming to agreement on the precise meaning of the terminology used to describe the collected data. Lack of tools to help researchers share and integrate data has also hampered data analysis. This situation has delayed improving diagnosis, intervention, and treatment before and after birth.

> **This would provide the foundation for the first clinical dataset for FASD...**

In Canada, prior to the start of the National Dataform project, no common database of FASD diagnoses existed and there was no standard reporting mechanism of findings among clinics. Dr. Sterling Clarren thought it would be helpful to determine whether it was even possible for clinics across Canada to collect the same data and to aggregate it to produce National reports on FASD in Canada. To accomplish this, Dr. Clarren contacted clinics across Canada to obtain forms used in FASD assessments and lead the development of common data forms; the **Universal FASDiagnostic Forms**. These forms were piloted in 2009 in six major FASD diagnostic centres. At that time, clinicians found using the Universal FASDataform challenging, but recognized the merit of the process.

In 2011, Dr. Clarren's Universal FASDataform Project received funding from the Public Health Agency of Canada's FASD National Strategic Project Fund to expand the pilot project in order to collect data for 9 months from all clinics in Canada willing to participate. This became the first existing patient-level database of individuals with FASD in the world and included approximately 250 files from 41 clinics.

A manuscript was published by the research team, documenting the process and the findings. Highlights were:
- The percent of individuals with Fetal Alcohol Syndrome was 2.1% of those with FASD diagnoses, which was lower than expected based on the literature.
- The level of disability was highly variable, but approximately 25% were much more impaired than the population is typically described.
- No specific patterns of functional disability were found to represent any significant subgroup of the individuals.
- An average of 13 recommendations for intervention and management were made for each patient in health, mental health, social services, and education.
- It was possible for clinics across Canada to collect and report on the same diagnostic data.
- Data of this kind was helpful with assuring consistency in diagnosis and with planning for improved patient outcomes.

## The National FASD Database Project: Current Status

Dr. Clarren's initial project revealed a number of recommendations for interventions and management for patients in health, mental health, social services and education. Data also revealed that diagnostic clinics would benefit from additional education and training related to the diagnosis of FASD to ensure the universal adoption of a standardized approach. In 2015, NeuroDevNet funded Dr. Jocelynn Cook to expand the DataForm project and to be consistent with the 2016 Canadian Diagnostic Guidelines. Significant work was required to recruit additional clinics so that the dataset was representative as well as to sustain the infrastructure for data collection, management and analysis.
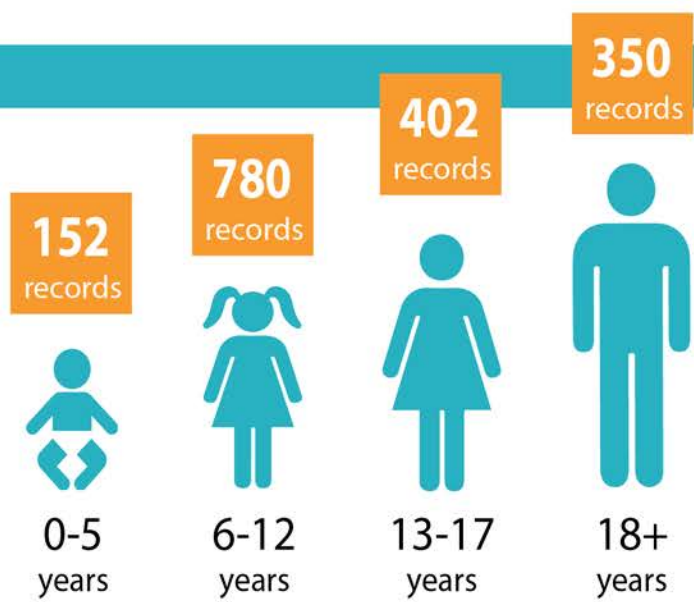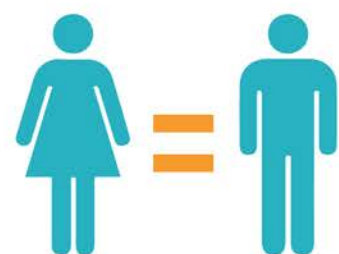
The FASD Dataform was streamlined and expanded based on comments and feedback from the stakeholders and was converted to an online platform. There are currently over 2,100 records in the database, being entered by volunteers at 29 diagnostic clinics across Canada! The research team is committed to recruiting more participating clinics, supporting those who are involved, providing data synthesis that are meaningful, using information to catalyze future work, and sharing findings with participants, families, researchers and policymakers to better understand FASD and to better support individuals and families.

# SNAPSHOT OF THE DATA

## Who's in the Database?

**2,211** records as of November 2019

**90.7%** of records correspond to an initial FASD assessment

**1,320** individuals had a diagnosis of FASD

**91.0%** of cases have confirmed PAE

## Distribution of Records

Equal numbers of males and females

**152** records — 0-5 years

**780** records — 6-12 years

**402** records — 13-17 years

**350** records — 18+ years

Please note that, due to missing data in some cases where records were incomplete, and some datasets being pulled from the database for analysis on different dates, the numbers will not always add up with simple math and the denominators will not always be the same. All statistics and numbers have been verified.
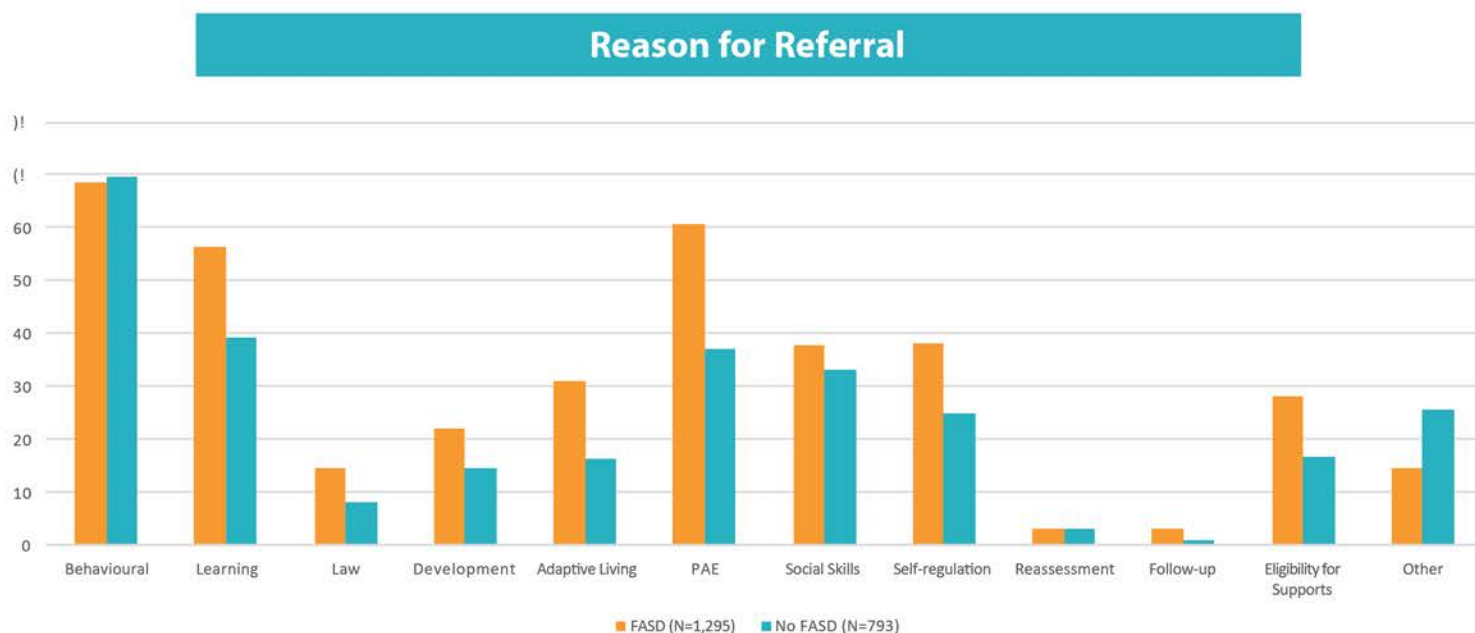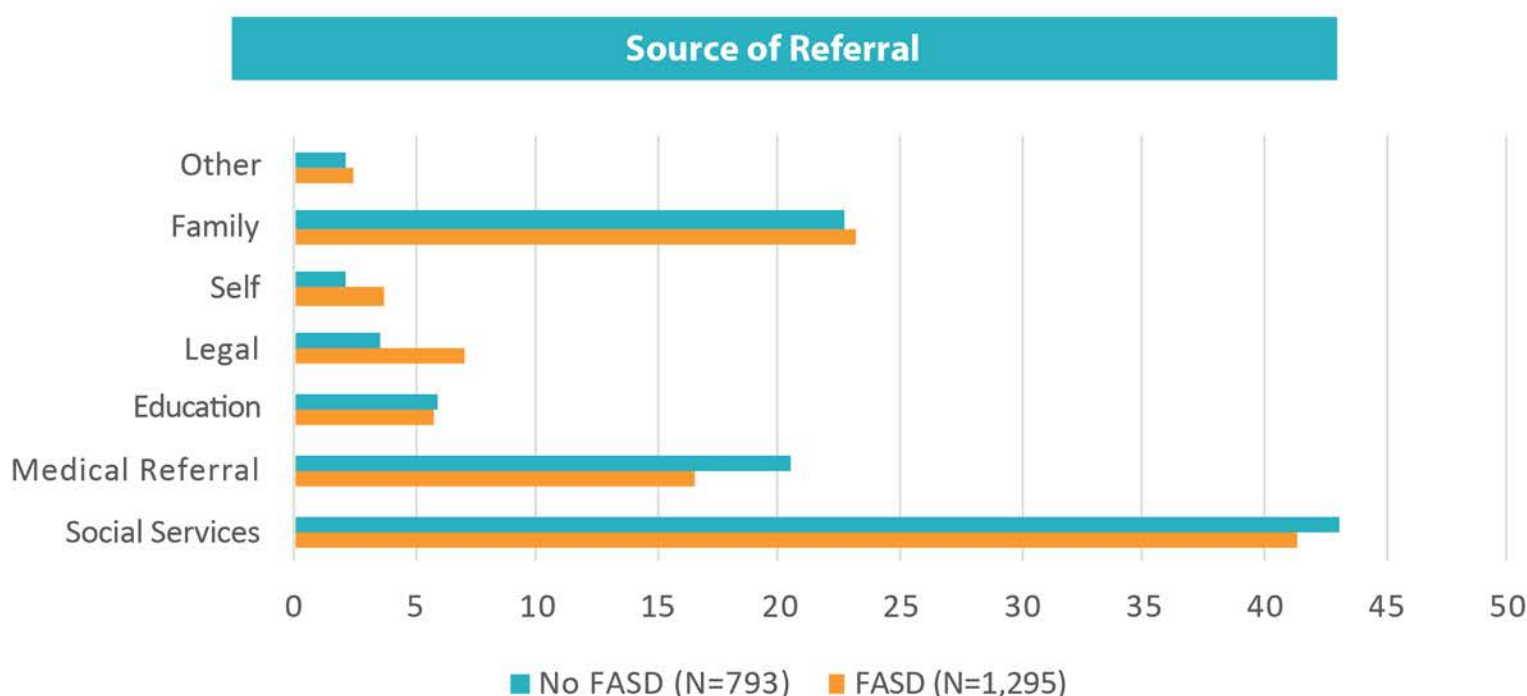
## Provincial Participation:

| | Number of Participating Clinics | Number of Records | Percent of Database |
|---|---|---|---|
| British Columbia | 2 | 37 | 1.7 |
| Alberta | 16 | 802 | 37.7 |
| Manitoba | 1 | 493 | 23.2 |
| Ontario | 6 | 596 | 28 |
| New Brunswick | 2 | 171 | 8 |
| Yukon | 1 | 16 | 0.8 |
| Northwest Territories | 1 | 13 | 0.6 |
| **Total** | **29** | **2,128** | **100** |

The research team was interested to learn where referrals for diagnosis were originating from and why individuals were being referred. This will help to identify systems where FASD may be over-represented (i.e., social services) or under-recognized, which "red flags" trigger a referral and if these differ across age groups, and where additional training and education related to screening and referral may be important.

The majority of individuals were referred for diagnosis because of behavioral issues, known prenatal alcohol exposure and learning difficulties. Most referrals came from social services, family and from healthcare providers, highlighting the critical role that these individuals play in recognizing the issues associated with FASD and advocating for diagnosis. Those with and without FASD tended to be referred from the same sources, although individuals with FASD were referred from legal more frequently.

## Source of Referral



Legend: ■ No FASD (N=793)  ■ FASD (N=1,295)

## Reason for Referral



Legend: ■ FASD (N=1,295)  ■ No FASD (N=793)

The FASD population in the National Database tends to live with biological family members and in foster care. Data show that different living situations in the child and adolescent populations do appear to influence the outcomes associated with prenatal alcohol exposure, which is similar to published literature. The table shows the distribution of living situations among children and adolescents with FASD in the database.

| Living Situation | n | % |
|---|---|---|
| Foster care (non-family member) | 184 | 27.7 |
| With other family members | 151 | 27.7 |
| Adoptive parents | 136 | 20.5 |
| With biological mother | 106 | 15.9 |
| With biological father | 54 | 8.1 |
| Group home | 34 | 5.1 |
| **Total** | **665** | **100** |

6%
38%
56%

■ FASD W    ■ FASD W/O    ■ No FASD
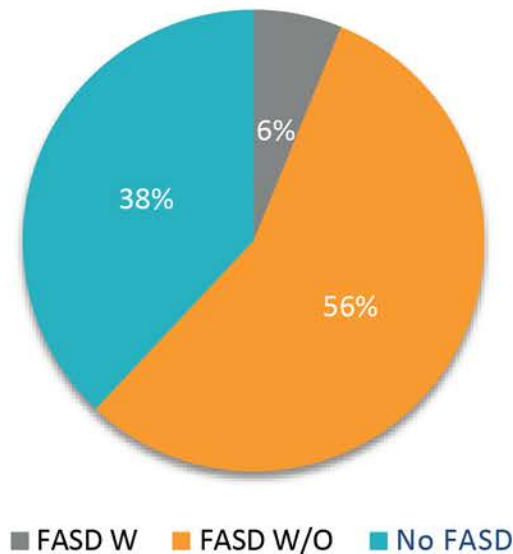
In the updated Canadian guidelines for diagnosis, the predictability of the presence of the 3 sentinel facial features for FASD was recognized, and thus confirmation of prenatal alcohol exposure was no longer required for a diagnosis if individuals had a thin upper lip, small palpebral fissures and a smooth philtrum.

It is important to note that other diagnostic systems require fewer than three facial features to receive a diagnosis of FASD (pFAS or ARND) even in the absence of confirmed prenatal alcohol exposure. That said, results from the National Database follow the trends identified in the literature with ~5-10% of the individuals diagnosed having all 3 sentinel facial features, which has been historically described as Fetal Alcohol Syndrome.

## Confirmation of Prenatal Alcohol Exposure (PAE)

|  | FASD (n=1,295) | No FASD (n=793) |
|---|---|---|
| Confirmed Absent | 0.2 | 2.2 |
| Confirmed Present | 98.8 | 78.2 |
| Unconfirmed | 0.5 | 10.7 |
| Unknown | 0.5 | 9 |
| Missing Data | 2 | 70 |

Data were also examined across age groups and by diagnoses. In August 2019, the distribution was as follows:

## By age groups (n=1,684)

| Diagnoses | 0-5 yrs | 6-12 yrs | 13-17 yrs | 18+ yrs |
|---|---|---|---|---|
| FASD | 30.3 | 52.8 | 64.4 | 76.9 |
| At Risk | 37.5 | 14.9 | 3.5 | 1.4 |
| No FASD | 32.2 | 32.3 | 32.1 | 27.7 |
| **Total Records** | **152** | **780** | **402** | **350** |

Individuals who received an FASD diagnosis tended to have more sentinel facial features than those without FASD, but there were no differences between the two groups when it came to fewer than all 3 features.

## Distribution of SFF in Records

|  | FASD | No FASD |
|---|---|---|
| Small Palperbral Fissures | 33% | 30% |
| Smooth Philthrum | 30% | 21% |
| Thin Upper Lip | 26% | 21% |

## Percentage of SFF in Records

| Number of SFF | FASD | No FASD |
|---|---|---|
| 0 | 42% | 48% |
| 1 | 25% | 26% |
| 2 | 14% | 14% |
| 3 | 12% | 4% |

## What does this mean to you?

There are a number of other neurobehavioural/physical teratogens that can affect fetal growth and development and that may also have synergistic effects with prenatal alcohol exposure. For example, we know that nicotine affects pregnancy, in particular, fetal growth and development; and that some prescription medications also have a similar impact. With the recent legalization of cannabis, we have become more interested in the implications of cannabis use during pregnancy, and we continue to recognize the complexity of polysubstance exposure. Because "other prenatal exposures" are captured in the database, we were able to determine that approximately 50% of those with FASD were only exposed to alcohol, and the other half were exposed to a combination of other substances in addition to alcohol. The following graph indicates when confirmation of exposure to other substances was indicated:



**Other Prenatal Exposures**

Legend: ■ No FASD (N=793) ■ FASD (N=1,295)
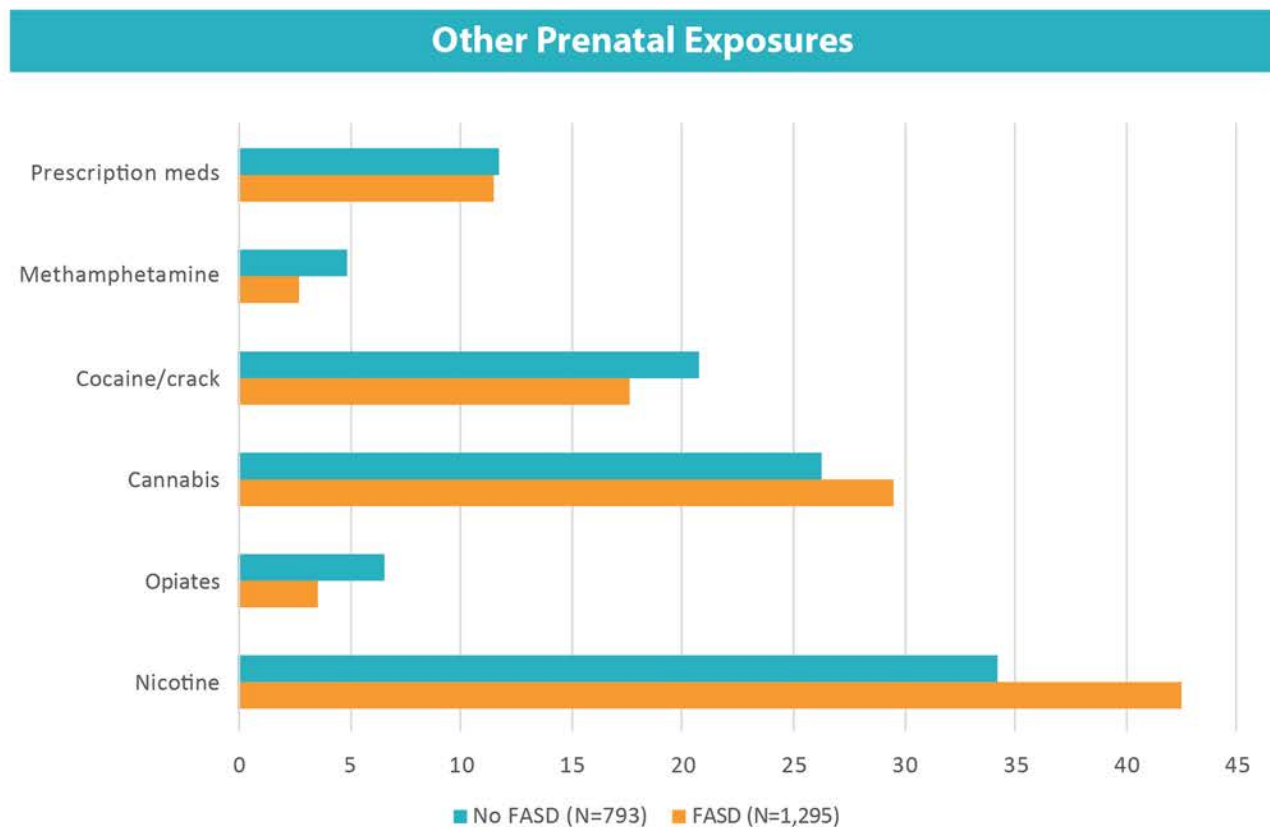
It is evident that, among those with FASD as well as those who did not meet the criteria for a diagnosis, exposure to other substances is common. It is important to note that this chart shows when **any** substance was present and may include other substances as well. For example, the "cannabis" number indicates the percentage of the sample group who had alcohol as well as cannabis exposure. Future analyses will be able to further segment the exposures into alcohol only, alcohol + cannabis, alcohol + cannabis + nicotine, etc. This will allow us to partition out the protective or additive factors of other substances on brain impairment, physical and/or mental health co-morbidities, adverse outcomes, etc. It also illustrates how complex prevention of FASD is, and the possible role of other prenatal exposures.
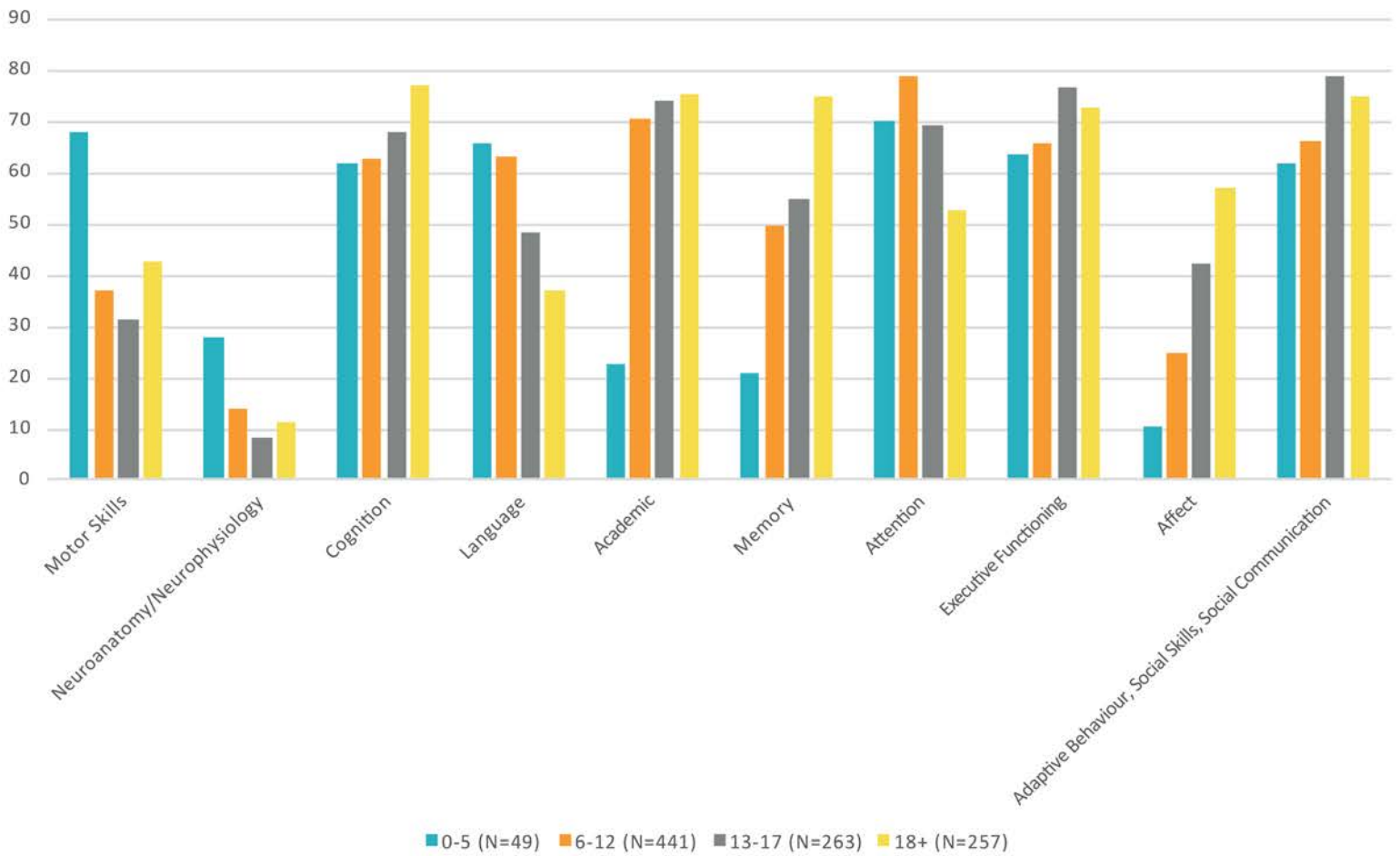
The evolution of the Canadian diagnostic guidelines resulted in some changes in the brain domains required as a "hit" in the diagnostic assessment. The data describing the brain profiles of individuals with FASD show that they are significantly more likely to have significant impairment in every brain domain compared to those without FASD. 48% of those with FASD had 6 or more brain domains impaired, suggesting that this population is very affected. Only 18% of those without FASD had 3 or more domains impaired.

Initial analysis suggest that the top 3 brain domains impaired differed across the ages, with Attention, Adaptive and Executive Function being the more frequent in those with FASD under the age of 18, and Cognition, Academic and Memory the most frequent in the adults with FASD. Future analyses will further break down the domains and the patterns across the ages and genders and will also seek to determine if there are relationships with comorbidities and adverse experiences.



**Domains Impaired**

No FASD (N=793)   FASD (N=1,295)
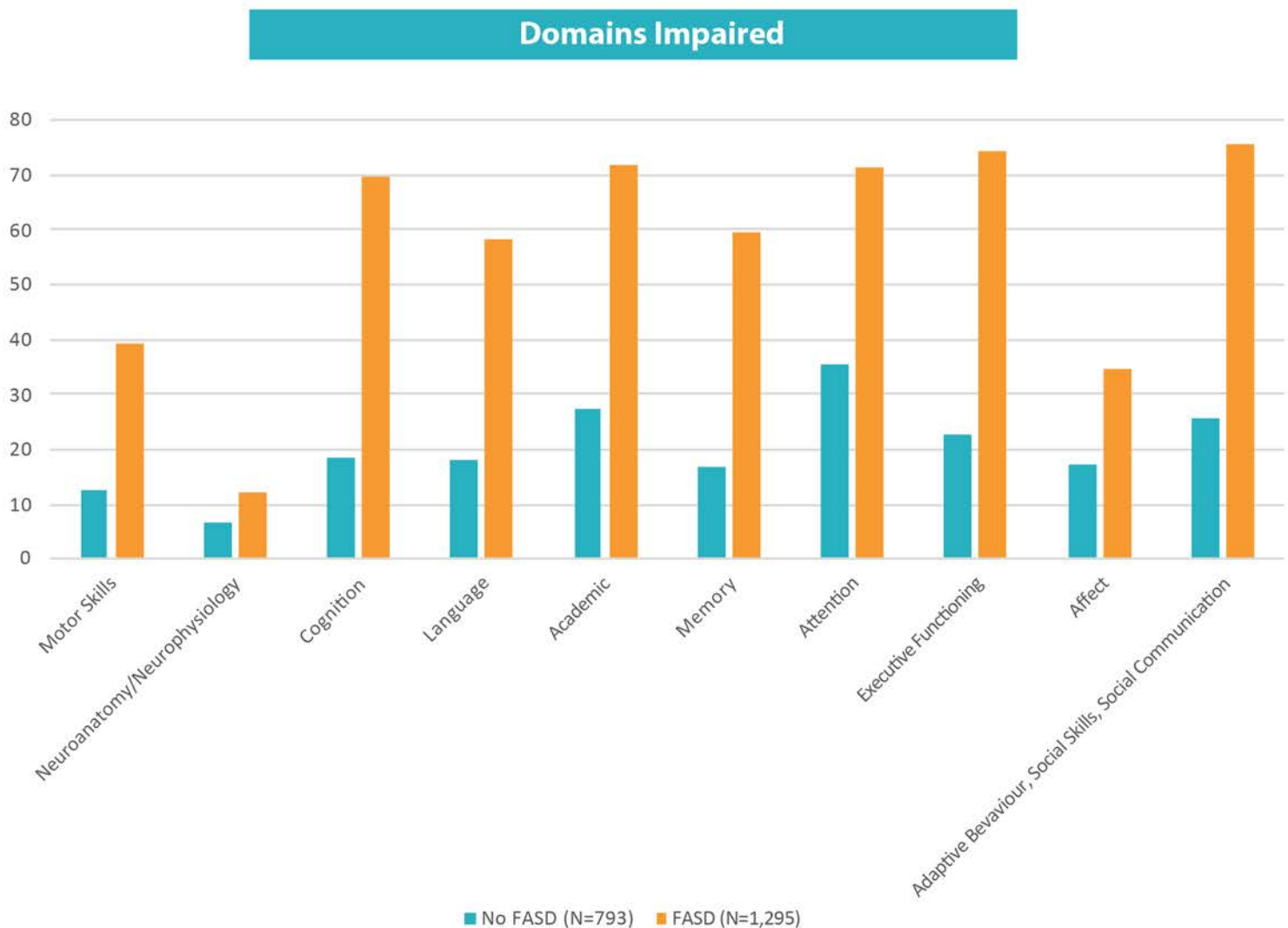
In fact, brain domains impaired indeed show differences across the different age cohorts with FASD, as one would expect. For example, it is difficult to thoroughly assess preschoolers for all brain domains and evidence of impairment becomes apparent as they grow older. Eventually, these data will be able to contribute to better understanding the sensitivity and specificity of these brain domains to PAE, as well as to inform diagnostic criteria and processes and tools that are perhaps more specific to difference ages.

## Brain Impairment Across Age Groups



Legend: 0-5 (N=49) · 6-12 (N=441) · 13-17 (N=263) · 18+ (N=257)

Categories: Motor Skills, Neuroanatomy/Neurophysiology, Cognition, Language, Academic, Memory, Attention, Executive Functioning, Affect, Adaptive Behaviour, Social Skills, Social Communication

It has been well-known for many years that individuals with FASD experience, more than the general population, a number of societal issues and adverse experiences. As would be expected, the types of these issues are different across ages. Adults tend to have justice, legal, employment, living and housing issues and school-aged children have trouble in school. These are the first data to illustrate, in Canada, the difficulties that individuals with FASD experience across the ages and provide critical information for anticipatory planning and interventions.

### Issues Being Experienced by Age Group



Legend: 18+ (N=257), 13-17 (N=263), 6-12 (N=441), 0-5 (N=49)
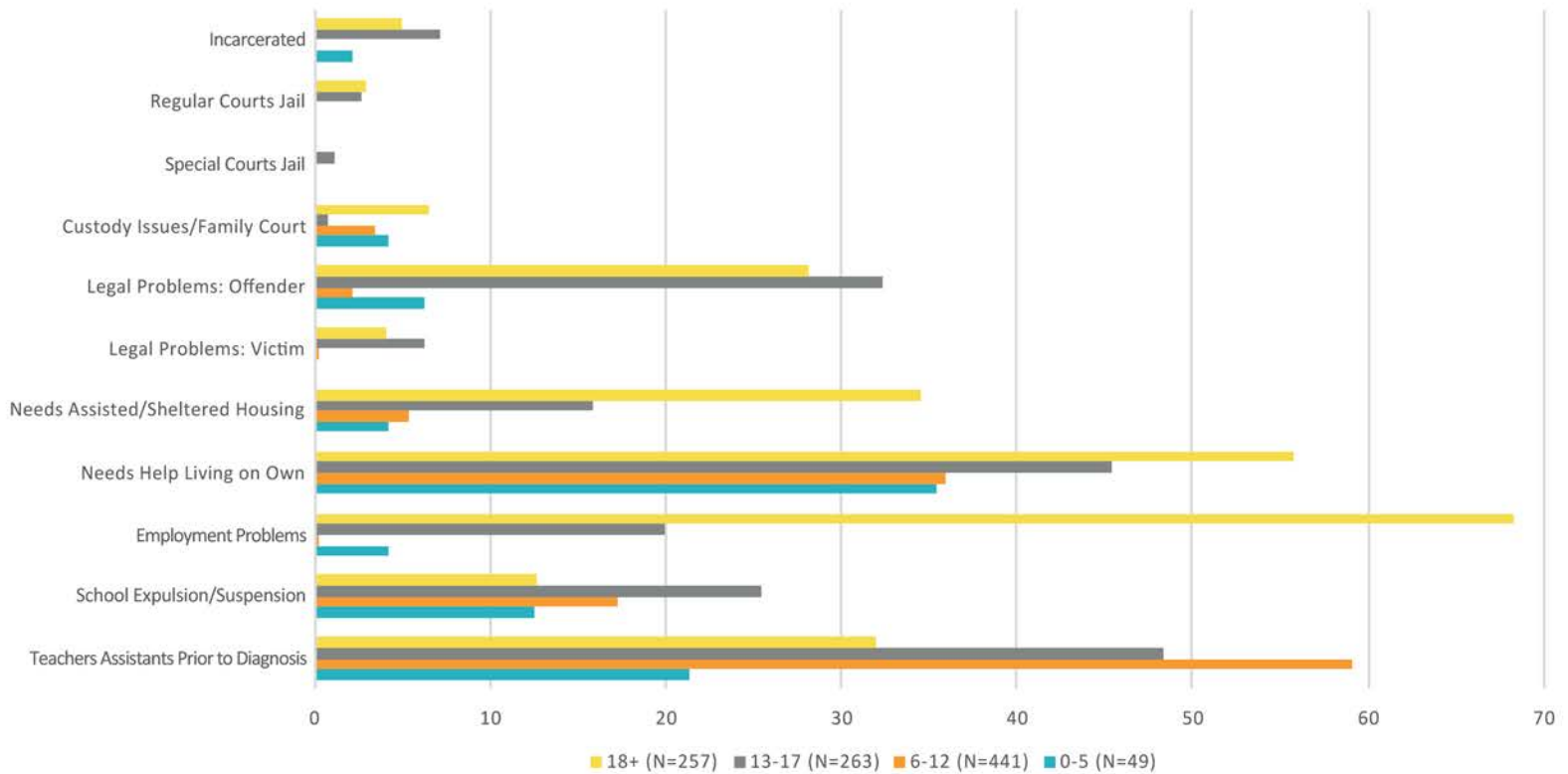
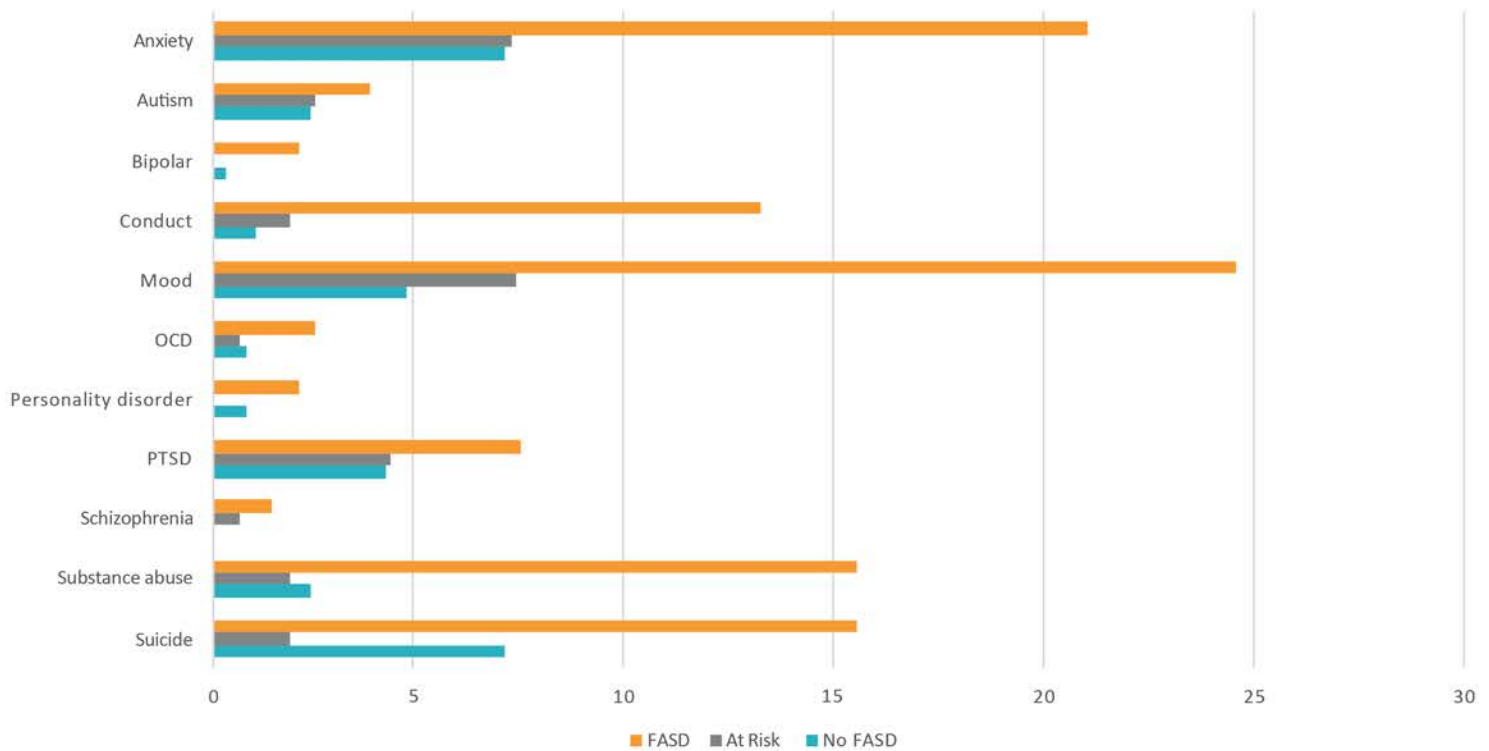## FASD and Mental Health Co-Morbidities

The over representation of mental health co-morbidities in the FASD population has been well-documented in other countries. These data show that this is similar in the Canadian cohort in our database. Mental health co-morbidities tend to be evident earlier and with a much higher prevalence in those with FASD. As individuals age, their mental health co-morbidities are more and more prevalent.

### Mental Health Across Ages



Legend: 0-5 (N=46)  6-12 (N=412)  13-17 (N=259)  18+ (N=269)
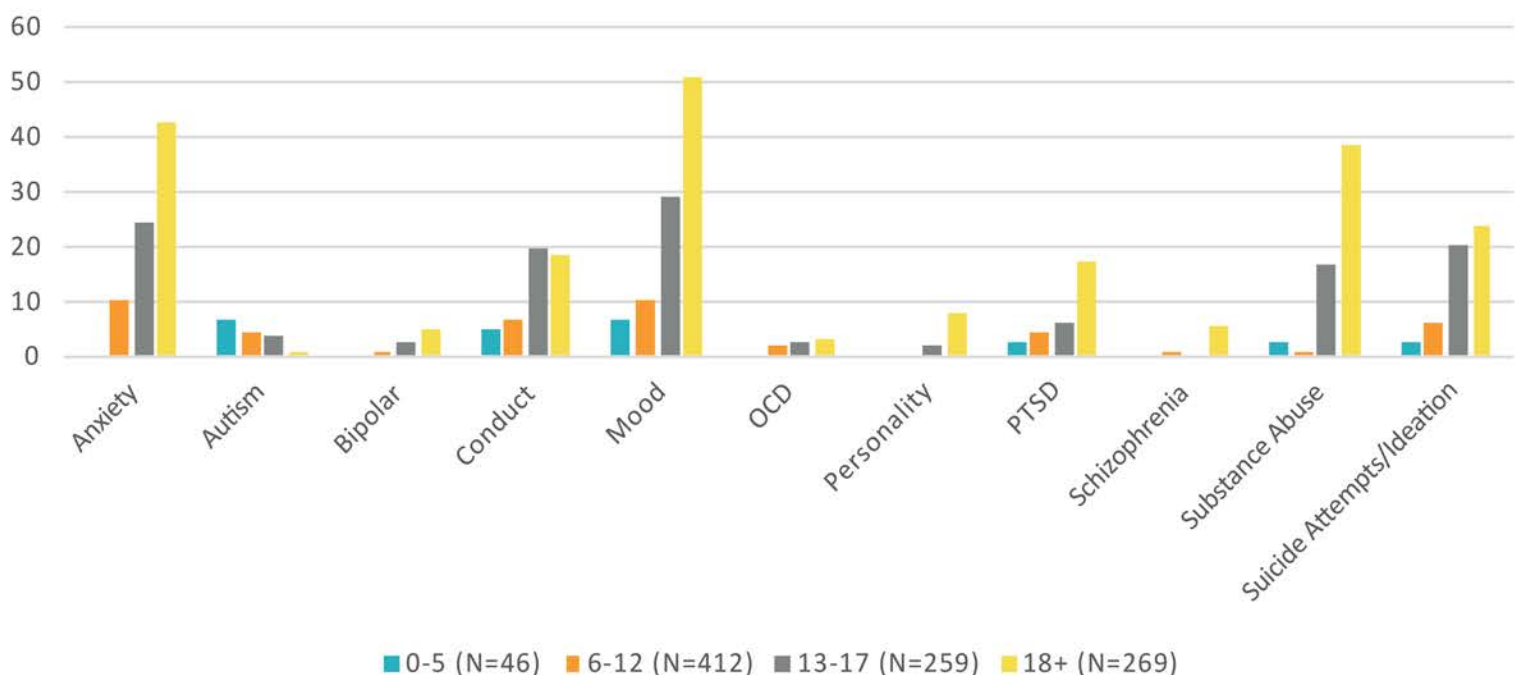
It is also important to note that individuals who are designated "At Risk" for FASD and those who do not have FASD have significantly fewer mental health diagnoses.

## Mental Health Co-Morbidities in Individuals with FASD



When talking about the rates of mental health co-morbidities, and their over representation in the FASD population, it is also important to report rates in the Canadian population at-large so that the impact is clear. Rates of mental health disorders experienced by those with FASD compared to the Canadian population are compared below. The differences are evident, and would likely be even more pronounced if they were broken out by age groups, with adolescents and adults having even higher rates. Coming soon…..

## Mental Health Co-Morbidities in Canada vs. Data from Dataform



**14**
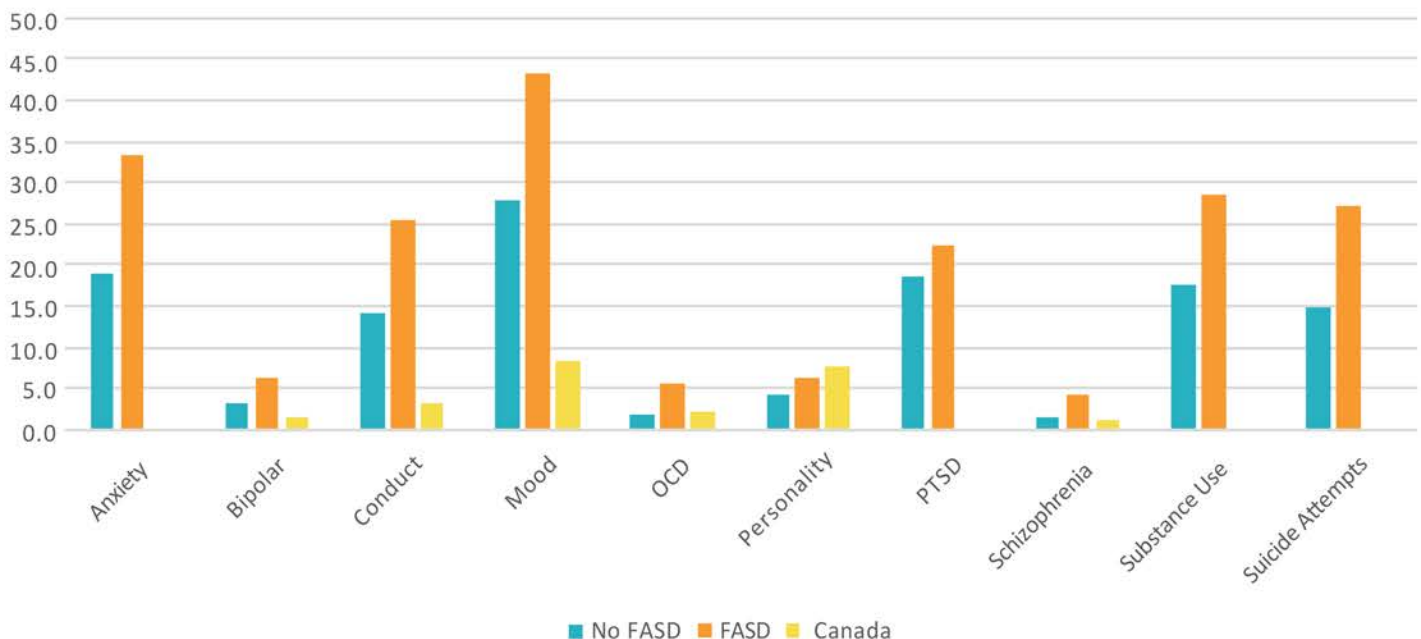
It has been recently reported that, in addition to the higher propensity of mental health co-morbidities, individuals with FASD also have a higher probability of physical health issues. We are still determining the rates of these ailments in the Canadian population and breaking them out across the age groups. More research is needed in this area, but there is enough evidence for clinicians to start asking their patients with FASD more questions about their physical symptoms and discussing how to best monitor and manage them.
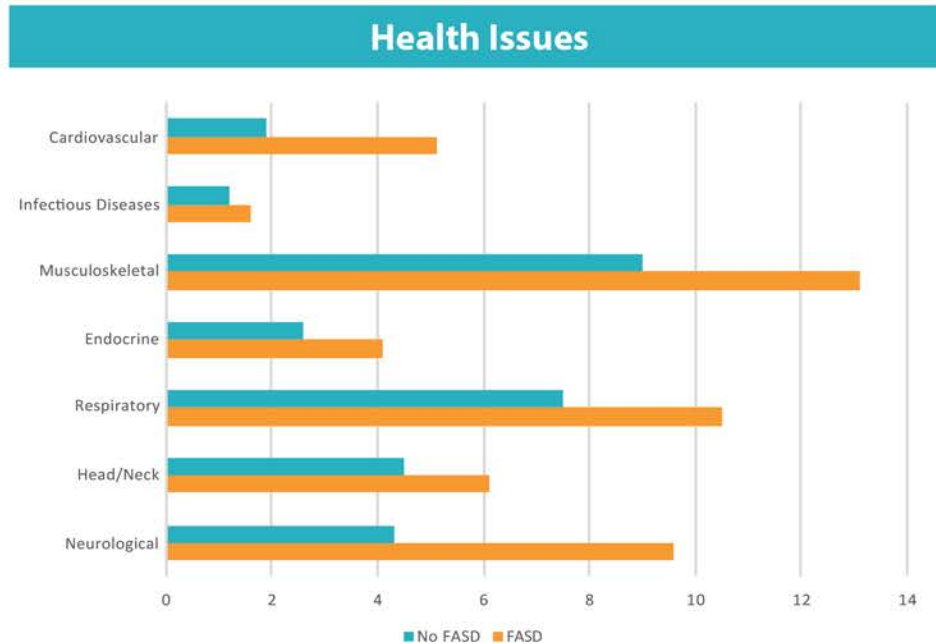
### Health Issues



It is also important to think about physical health issues across the life span, and learning more about when conditions may present as an individual ages. As would be anticipated, the figure below shows that adolescents with FASD experience more physical health issues. Future studies can also determine relationships between physical health issues and other health/behavioural/social factors associated with FASD, as well as to compare rates to the general population.

### FASD and Health Issues by Age
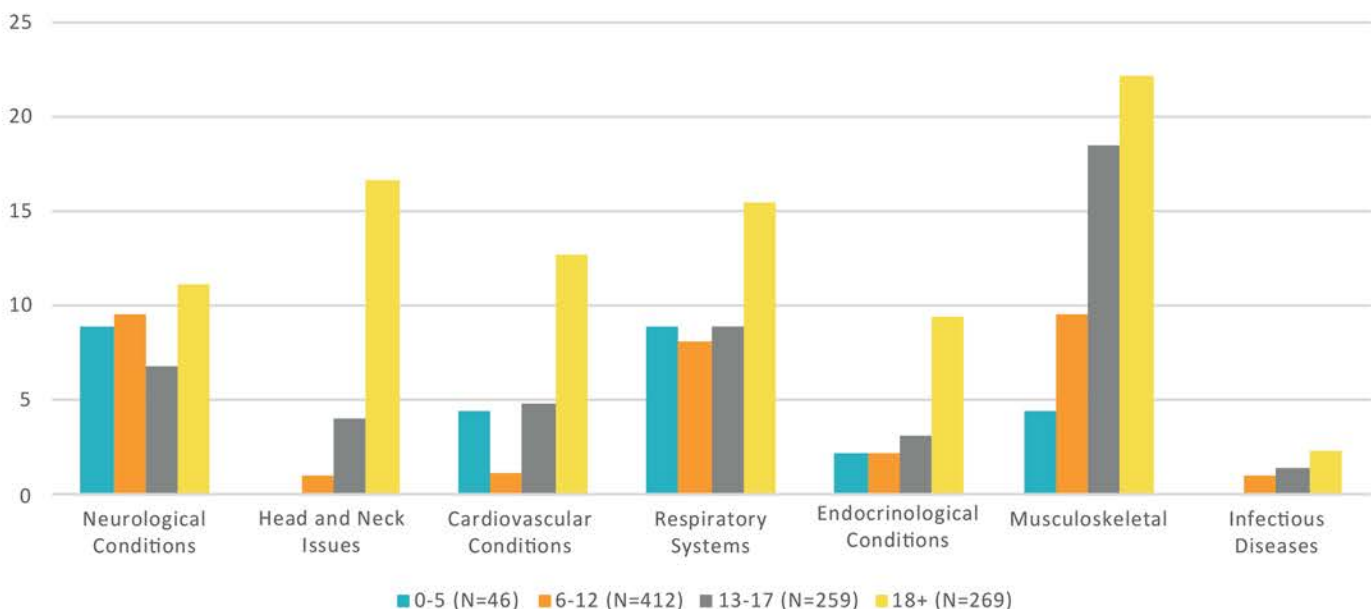
With the number of records in the database being sufficient to provide enough power to ask even more questions, we have begun to further segment the data. For example, we have begun to explore relationships and/or impact to better understand our FASD population and to more effectively describe where anticipatory guidance for physical and/or mental health intervention(s) may be beneficial, as well as the permissive and protective factors. Some sneak peak (and still preliminary!) findings are:

**1** Children with FASD living in the child welfare system have a higher rate of legal problems, experiences of abuse, alcohol and nicotine use compared to those living with biological/adoptive family.

**2** Adolescents and adults seen for an FASD assessment presented with high rates of difficulties in daily living, the most common of which included requiring supports to live independently, employment problems, and legal problems as an offender, in addition to high rates of both alcohol misuse and substance misuse.

**3** Among those diagnosed with FASD, rates of difficulties were greater among those with intellectual functioning in the disabled range (IQ < 70) and among men, while generally similar among those presenting with and without three sentinel facial features.

**4** Individuals with FASD and Affect Regulation (AR) deficits were more likely to have mental health problems such as mood disorders, conduct disorder and attachment disorder. They were also more likely to have PTSD or a prior suicide attempt. AR deficits were most commonly found in those with greater overall neurodevelopmental impairment. Having AR deficits was associated with diagnosis of FASD at a later age. Gender and IQ were not related to AR deficits.

**5** Individuals with FASD who were also exposed to cocaine prenatally tend to have more language and neuroanatomy/neurophysiology deficits than those exposed to alcohol alone. Those exposed to cannabis and alcohol had more AR impairment, but less adaptive function and less memory impairment that the alcohol-only exposed group.
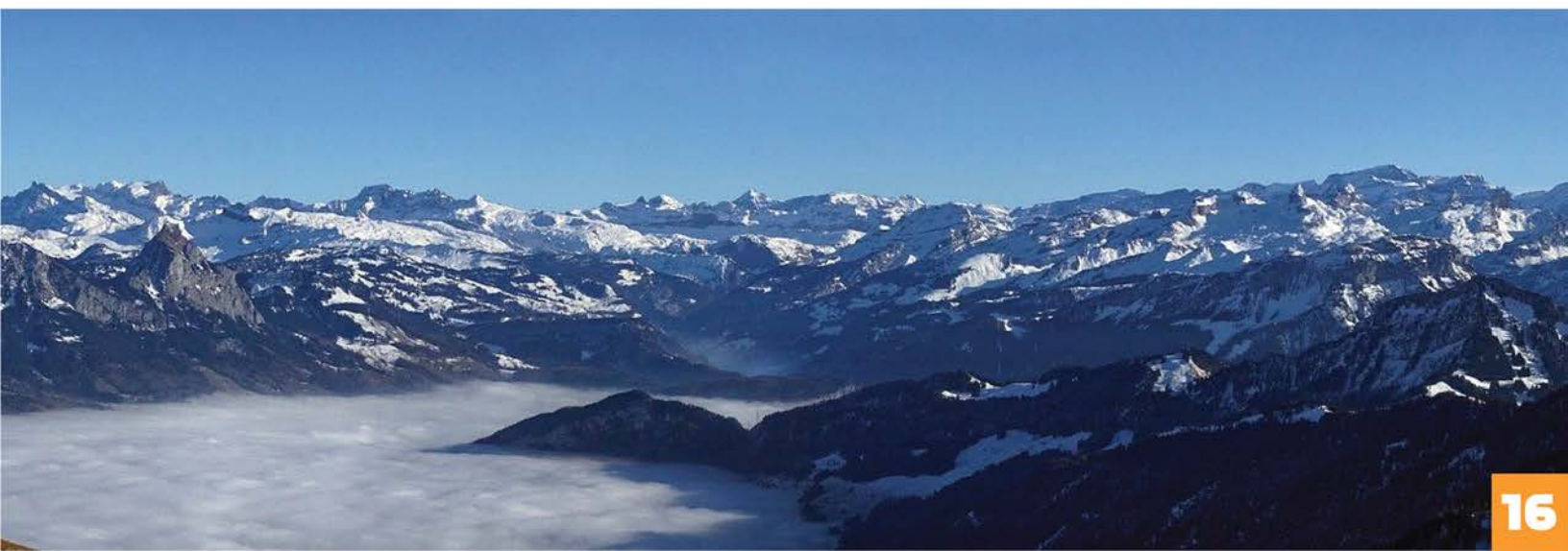
## Future Analyses

Future data analyses are becoming more and more possible as the data set grows and becomes more powerful. Some areas for exploration include:

- Correlations between brain domains and mental health co-morbidities, across ages and gender
- Correlations with brain domains and adverse outcomes, across ages and gender
- Implications of other prenatal exposures on mental health co-morbidities
- Mapping adverse outcomes to patterns of brain impairment and co-morbidities
- Profiles of individuals in care vs not in care
- Profiles of individuals with contact with justice system, including offenders, victims and those incarcerated, including patterns of brain impairment, co-morbidities, etc
- Ages where specific brain domains become measurably impaired

## Clinic Updates

The New Brunswick Centre of Excellence for FASD (Vitalite NB) was recently awarded the Health Standard Organisation Leading Practice designation from Accreditation Canada! They were also awarded the inaugural Claudette Bradshaw Innovation Award to recognize their groundbreaking Dream Catcher Service Delivery Model. Designed in partnership with Indigenous elders, the Dream Catcher model is a holistic, people-centered approach that ensures that Indigenous clients with FASD and those surrounding them are involved in supporting the individual throughout their lifetime. The Centre of Excellence has implemented this approach with all of our clients across the province.

### Congratulations Team!



Photo of the NB FASD team and stakeholders at the Claudette Bradshaw Innovation Award ceremony in New Brunswick