Difficulties in daily living experienced by adolescents, transition-aged youth, and adults with Fetal Alcohol Spectrum Disorder

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1 **Difficulties in Daily Living Experienced by Adolescents, Transition-Aged Youth, and**
2 **Adults with Fetal Alcohol Spectrum Disorder**

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Abstract

Background: Individuals with fetal alcohol spectrum disorder (FASD) experience a range of problems in their cognitive, affective, and physical functioning following prenatal alcohol exposure (PAE), in addition to multiple complex difficulties in daily living that impact well-being. Using the Canadian National FASD Database, we sought to profile a range of difficulties in daily living, along with risk factors, in a large cross-sectional cohort of adolescents, transition-aged youth, and adults with PAE, of which a subset was ultimately diagnosed with FASD.

Methods: We summarized data for 9 *current* difficulties in daily living reported at the time of diagnostic assessment for 726 individuals with PAE assessed at 26 FASD diagnostic clinics across Canada, including 443 adolescents (12 to 17 years), 135 transition-aged youth (18 to 24 years) and 148 adults (25 to 60 years). Difficulties included problems related to school disruption, employment, independent living needs, supportive or sheltered housing, legal problems with victimization, legal problems with offending, incarceration, alcohol misuse, and other substance misuse. Risk factors included age, gender, living placement, postnatal trauma, and neurodevelopmental impairment.

Results: Across the full PAE sample, adolescents, transition-aged youth, and adults presented with high rates of difficulties in daily living, including independent living support needs (63%), alcohol misuse (38%), other substance misuse (46%), employment problems (37%), legal problems with offending (30%), assisted or sheltered housing (21%), school disruption (18%), legal problems with victimization (4%), and incarceration (3%). Difficulty rates were similar for those with FASD irrespective of diagnosis (e.g., with or without sentinel facial features), but rates greater for adults, and those with low overall intellectual functioning

(IQ < 70). Controlling for age and IQ, cumulative difficulty was independently associated with gender, living placement, and neurodevelopmental impairment.

Conclusions: Adolescents, transition-aged youth, and adults with FASD experienced a range of substantial and complex difficulties at the time of their diagnostic assessment, signaling a high level of service needs. These findings underscore the importance of developmentally informed assessment continued through childhood, as well as ongoing functional and needs-based service provision as youth with FASD transition to adulthood and beyond.

Key Words: Fetal Alcohol Spectrum Disorder, Prenatal Alcohol Exposure, Adaptive Functioning, Difficulties.

Introduction

Individuals with FASD experience a range of difficulties in their cognitive, affective, behavioural, and adaptive functioning, in addition to possible physical features (e.g., facial dysmorphology) as a result of prenatal alcohol exposure (PAE) (Cook et al., 2016; Mattson et al., 2019). Conservative North American prevalence estimates range from 2 to 5%, resulting in annual economic impact estimates between \$1.8 and 9.7 billion across sectors in Canada (May et al., 2018; Popova et al., 2015, 2019; Thanh & Jonsson, 2015). Combined with the significant vulnerability associated with the disability, these statistics underscore the substantial degree of support required to ensure that people with FASD can effectively access their strengths and mitigate against adverse outcomes. In day-to-day terms, supporting people with FASD often requires a high level of care and responsibility undertaken by families and caregivers, in addition to substantial resources from more formalized institutions and systems of care (Bobbitt et al., 2016; Cleversey et al., 2017).

Globally, the clinical guidelines and diagnostic language used to characterize individuals with PAE and FASD vary considerably. While the Canadian FASD Diagnostic Guideline applies the FASD label in a diagnostic sense, other systems nest a range of terms under a broader diagnostic umbrella (see Coles et al., 2016). Despite these differences, one of the hallmark difficulties among people with FASD is neurodevelopmental impairment (Mattson et al., 2019). Under the current Canadian FASD Diagnostic Guideline, neurodevelopmental functioning in 10 domains is assessed, including motor skills; neuroanatomy/neurophysiology; cognition (IQ); language; academic achievement; memory; attention; executive functioning; affect regulation; and adaptive behaviour, social skills, and/or social communication (Cook et al., 2016).

Many people with FASD struggle with skills of everyday living, also referred to as adaptive functioning (Doyle et al., 2019; Mattson et al., 2019). In the absence of appropriate supports, these everyday problems in communication, daily living skills, and socialization can contribute to adverse outcomes (Ali et al., 2018; Astley, 2004; Jirikowic et al., 2008; Sakano et al., 2019; Temple et al., 2011). Though the field has traditionally adopted a deficit-focused model of disability, people with FASD also have a range of strengths and resiliencies that can be leveraged to support successes in their everyday lives (Currie et al., 2016; Pei et al., 2016; Rogers et al., 2013). FASD is a heterogeneous disability, with substantial variability between and within individuals (e.g., Ali et al. 2018). Coupled with the often-hidden nature of the disability (i.e., no physical indicators) and limited assessment and diagnostic resources, identifying the potential abilities and needs of individuals with FASD can be difficult. This underscores the importance of research characterizing commonly experienced stressors, risks, and difficulties in daily living within this group, that left unsupported, may lead to adverse outcomes (Clarren & Lutke, 2008).

Despite a proliferating evidence base focusing on children with FASD, there remains a dearth of quality research on the daily experiences and needs of older adolescents and adults (Lynch et al., 2015). This research is particularly important in the context of rapidly unfolding maturational and developmental stressors, and increased expectations for independence and responsibility as youth transition to adulthood, with compounding impact for youth with disabilities (Osgoode et al., 2005). The decrease in service availability for youth with disabilities of all kinds during this critical period can present serious challenges (Burnside and Fuchs, 2013). In their seminal study, Streissguth and colleagues (1996, 2004) profiled adverse life experiences in a cohort of 253 clinically referred adolescents and adults with FASD. They found high rates of

disrupted school experiences (61%); trouble with the law (60%); confinement in correctional, psychiatric, or alcohol/drug inpatient settings (50%); inappropriate sexual behaviour (49%); and alcohol/drug problems (35%). Having a diagnosis of fetal alcohol effects (vs. fetal alcohol syndrome) and being male increased risk for disrupted school experiences and trouble with the law, while experiences of victimization increased odds for inappropriate sexual behaviour and alcohol/drug problems. Protective factors included earlier age at diagnosis and being raised in a stable home environment. Lower overall intellectual functioning (e.g., $IQ < 70$) was also linked with better outcomes across 4 of the 5 adversities.

Examinations of clinically referred children, and to a lesser degree, adolescents and adults with PAE, have shown similarly high rates of deficits in daily living skills, communication, and socialization, as well as behavioural problems, limited education and vocational achievement, and substance misuse, that are not fully accounted for by low overall intellectual functioning (Day et al., 2013; Famy et al., 1998; Fast et al., 1999; Rangmar et al., 2015; Temple et al., 2011). Most research about adaptive functioning in adults with FASD has focused on clinically referred samples, which may not generalize to those who do not present at a clinic. However, Lynch, and colleagues (2015) assessed day-to-day adaptive functioning and adult role entry in adults with PAE recruited for research and found that they experienced difficulties related to educational attainment, employment, and lower socioeconomic status, in addition to more specific difficulties such as dealing with money and obtaining a driver's license. Those who were less affected physically by PAE (but had significant cognitive impacts) showed the greatest level of difficulty, and men with PAE were particularly at risk for difficulties in daily living and transition to adult roles. Doyle et al. (2019) also recently found impaired adaptive functioning

among children and youth aged 6 to 18 years with heavy PAE relative to nonexposed controls, with deficits apparent across levels of IQ.

The Current Study. In this study, we aimed to profile difficulties in daily living experienced by a large sample of adolescents, transition-aged youth, and adults with PAE from the Canadian National FASD Database. We sought to ascertain rates of difficulty in daily living across a range of diagnostic outcomes and to explore difficulty profiles based on possible risk factors for those diagnosed with FASD, including age, gender, IQ, neurodevelopmental impairment, and postnatal trauma. Given limited empirical research in this area, we undertook an exploratory approach in addressing our research questions.

Materials and Methods

Study design. The Canadian National FASD Database (the Database) is an ongoing data repository characterizing clinical and diagnostic findings for individuals of all ages presenting for an FASD assessment in Canada. The Database includes records generated over 2 data collection waves between 2010 and 2019 (with ongoing entry), and the bilingual, (English and French) online platform receives information from 26 clinics across 7 Canadian provinces and territories. Data for the current study includes cases assessed between 2016 and 2019 using the current (2016) Canadian FASD Diagnostic Guideline. Thus, all individuals were evaluated by an interdisciplinary team across the same diagnostic features (e.g., confirmed PAE above risk levels¹, sentinel facial features (SFF)², and neurodevelopmental functioning in 10 domains, Table 1) and classifications (FASD with Sentinel Facial Features [+SFF], FASD without SFF [-SFF],

¹ Above-risk PAE threshold is defined as ≥ 7 standard drinks per week, or ≥ 2 episodes of drinking of ≥ 4 drinks on the same occasion under the Guideline (Cook et al., 2016). FASD + SFF may be diagnosed in the absence of confirmed above-risk PAE given the specificity of simultaneous presentation of three SFFs to PAE.

² Palpebral fissure length ≥ 2 standard deviations below the mean ($< 3^{\text{rd}}$ percentile), philtrum rated 4 or 5 on 5-point scale of the University of Washington (UW) Lip-Philtrum Guide, upper lip rated 4 or 5 on a 5-point scale of the UW Guide (Astley, 2004).

and a designation for those considered “At Risk for Neurodevelopmental Disorder [NDD] and FASD, associated with PAE”). For the current study, we included cases with confirmed PAE and diagnostic outcomes and excluded cases where data for age was missing.

Sample. The final sample ($N = 726$) included adolescents ($n = 443$, 61%, 12 to 17 years), transition-aged youth ($n = 135$, 19%, 18 to 24 years) and adults ($n = 148$, 20%, ages 25 to 60 years) (Table 2). Age differed significantly by diagnostic group, $F(3, 722) = 33.96$, $p < 0.001$, $\eta^2 = 0.12$. Those in the FASD + SFF group ($M = 28.1$, $SD = 12.4$) were significantly older than those in the FASD-SFF ($M = 20.1$, $SD = 8.8$, $p < 0.001$), At Risk for NDD/FASD ($M = 14.6$, $SD = 4.78$, $p < 0.001$), and not diagnosed groups ($M = 16.5$, $SD = 6.5$, $p < 0.001$). Those with FASD-SFF were also significantly older than those At Risk for NDD/FASD ($p = 0.025$), and those not diagnosed ($p < 0.001$), while age for the At Risk for NDD/FASD and not diagnosed groups did not significantly differ ($p = 0.780$). As such, we controlled for age in analyses comparing diagnostic groups. Just under half of the sample was female ($n = 306$, 43%)³ with no differences in gender between diagnostic groups. The sample identified with a variety of ethnocultural backgrounds.

The most common living arrangements included residing with biological parent(s) ($n = 136$, 19%), another family member ($n = 132$, 18%), or in foster care ($n = 121$, 17%). Most ($n = 629$, 87%)⁴ individuals completed an initial diagnostic assessment (vs. a re-assessment or follow-up evaluation). Common referral sources included social service agencies ($n = 311$, 44%), families and caregivers ($n = 142$, 20%), and the legal system ($n = 107$, 15%), and common referral reasons included confirmed PAE ($n = 482$, 66%), behavioural issues ($n = 448$, 62%),

³ Overall N for gender is 719, as one individual reported non-binary gender identity and was excluded from analyses. Data were also missing for 6 cases.

⁴ Overall N for sample characteristics varies. For living arrangement, $N = 720$ with missing data for 6 cases. For type of assessment, $N = 724$ with data missing for 2 cases. For referral source, $N = 714$, with missing data for 12 cases.

difficulties with learning ($n = 370$, 51%) or social skills ($n = 284$, 39%), and establishing service-eligibility ($n = 275$, 38%). Data comprised entries for clinics from 7 provinces and territories spanning 4 regions, including Western and Northern Canada (4%), Central Canada (20%), the Prairies (71%), and Atlantic Canada (5%).

Neurodevelopmental domains. The 10 neurodevelopmental domains from the Guideline are captured in the Database categorically (significantly impaired; not significantly impaired; not assessed; incomplete information) based on all information considered during the diagnostic assessment. For the current study, each domain was evaluated dichotomously (significantly impaired vs. not), using only complete data in the denominator. Cases where a domain was either not assessed or considered incomplete were excluded listwise. A cumulative neurodevelopmental impairment score (out of 10) was also calculated by summing impaired domains. The Database also includes a categorical field for IQ based on results from standardized testing (IQ < 70; 70; 71 to 85; > 85; and unable to calculate). These fields were trichotomized for the current study (< 70, 70 to 85, > 85), and cases with incomplete data (e.g., missing data, unable to calculate) were excluded listwise.

Difficulties in daily living. The Database characterizes multiple difficulties that individuals may have been experiencing at the time of their assessment (*not* lifetime ratings). These include the following: (i) suspension or expulsion from school (school disruption); (ii) employment problems; (iii) needing help to live independently (independent living needs); (iv) needing assisted or sheltered housing (housing problems); (v) legal problems with victimization; (vi) legal problems with offending; (vii) incarceration; (viii) alcohol misuse; and (ix) misuse of other substances (coded as any misuse of cannabis; opiates; solvents; crack; and “other” drugs). Difficulties included in the Database were informed by a review of common adversities reported

across clinical FASD samples (e.g., Lynch et al., 2015; McLachlan et al., 2016; Temple et al., 2011; Streissguth et al., 2004), consultation with clinical teams and experts, and the practical need for data entry efficiency. In the Database, difficulties are rated categorically (yes; no; unknown; and “to be followed-up after clinic”). For the current study, cases with positive endorsement in the numerator and clear negative endorsement for the denominator were considered, and cases with missing or “unknown” data were excluded listwise. A cumulative difficulty score was also calculated (out of 9) by summing positively endorsed difficulties, with cases excluded listwise where data were unknown/missing data for all 9 difficulties.

Risk factors. Several potential risk factors previously linked with difficulties in everyday living were explored for individuals diagnosed with FASD (Lynch et al., 2015; Streissguth et al. 2004; Temple et al., 2011). These included age (adolescents: 12 to 17 years; transition-aged youth: 18 to 24 years; adults: 25 + years), gender (male vs. female), and overall intellectual functioning (extremely low: IQ < 70; borderline: 70 to 85; low average and greater: >85). Current living placement was evaluated as a proxy for quality and stability of caregiver and home living circumstances. Placements were coded dichotomously, comparing individuals living with a parent or other family member (biological parents; adoptive parents; or other biological family members), with those living in “system” placements or independently (foster care; group home; custody; homeless; other). Postnatal trauma was also considered by creating a composite dichotomous variable combining Database fields for postnatal trauma and history of physical or sexual abuse (present vs. absent).

Ethics. Ethics approval was obtained from the Ottawa Health Science Network Research Ethics Board (protocol # 20160423-01H) and the University of Guelph Research Ethics Board (#19-07-032). Clinics participating in the Database enter de-identified data directly into the web

form following training from a member of the Database project research team (led by JC). No identifying information for participants (personal or health) is included in Database.

Analyses. Descriptive statistics were examined to characterize the sample for both continuous and categorical data. Logistic regression was used to evaluate risk factors and neurodevelopmental domains as predictors of difficulties, and linear regression was used to examine associations between risk factors and cumulative difficulty. Significant associations were then assessed using ANCOVA and evaluation of post hoc comparisons based on estimated marginal means using a Bonferroni correction. Region was included in all analyses as a covariate owing to differences in difficulty profile. Age was included as a covariate for analyses comparing diagnostic outcomes. Stepwise hierarchical logistic regression was used to assess the independent contribution of risk factors for individual difficulties, controlling for region, age, and IQ, given anticipated overall difficulty linked with developmental opportunity and globally impaired intellectual ability. Stepwise hierarchical linear regression was used to determine the independent contribution of risk factors on cumulative difficulty, controlling for region, age (as a squared term due to possible nonlinear association with difficulty), and IQ. Effect sizes (phi coefficient, partial eta squared, Cohen's d and f^2) and 95% confidence intervals are reported. Statistical analyses were conducted using IBM SPSS (IBM Analytics, Armonk, NY) version 26.0 for Mac.

Results

Sample characteristics. The sociodemographic characteristics of our sample were representative of the overall Database. Altogether, 10% ($n = 73$) of cases were diagnosed with FASD + SFF and 62% ($n = 452$) were diagnosed with FASD-SFF (see Table 2). Another 21 individuals (3%) were flagged At Risk for NDD/FASD, and 180 (25%) were not diagnosed with

FASD. Across the full sample, the most commonly impaired neurodevelopmental domains were adaptive behaviour, social skills, and/or social communication (66%); executive functioning (63%); academic achievement (61%); attention (60%); and cognition (57%).⁵ Widespread cumulative neurodevelopmental impairment was evident across the overall sample ($M = 4.41$, $SD = 2.29$), with significantly higher scores in the FASD + SFF group ($M = 6.05$, $SD = 2.09$) compared to the FASD-SFF ($M = 5.27$, $SD = 1.63$, $p = 0.001$), At Risk for NDD/FASD ($M = 2.62$, $SD = 1.24$, $p < 0.001$), and not diagnosed groups ($M = 1.77$, $SD = 1.63$, $p < 0.001$), $F(3, 721) = 209.86$, $p < 0.001$, $\eta^2 = 0.47$. Over one-third ($n = 265$, 40%) of the sample presented with IQ scores lower than 2 standard deviations below the population mean (i.e., <70), a criterion commonly used when considering a diagnosis of intellectual disability.⁶ Those diagnosed with FASD (+/- SFF) accounted for 97% of these cases ($n = 256$), with higher rates in those diagnosed with FASD + SFF ($n = 46$, 65%) compared to those with FASD-SFF ($n = 210$, 50%). Half of the sample had experienced postnatal trauma ($n = 366$, 50%).

Everyday difficulties. Difficulties were variably endorsed across the sample. The most frequently endorsed included independent living needs ($n = 406$, 63%), substance misuse ($n = 276$, 46%), alcohol misuse ($n = 215$, 38%), employment problems ($n = 241$, 37%), legal problems with offending ($n = 210$, 30%), housing problems ($n = 138$, 21%), and school disruption ($n = 116$, 18%, Table 3, Figure 1).⁷ Most individuals ($n = 583$, 81%)⁸ experienced at

⁵ Sample size varies for each neurodevelopmental domain (ranging from $n = 635$ for neuroanatomy/neurophysiology to $n = 707$ for academic achievement) due to domains not having been assessed ($n = 7$ for cognition to $n = 59$ for neuroanatomy/neurophysiology), and missing data ($n = 5$ for academic achievement to $n = 32$ for neuroanatomy/neurophysiology).

⁶ $N = 668$ for IQ as IQ, with 35 'unable to calculate' cases, missing data for 23 cases.

⁷ Sample size varies for each difficulty, ranging from $N = 562$ for alcohol misuse, to $N = 705$ for legal difficulties with offending, due to missing data, see Table 3.

⁸ $N = 722$ for cumulative difficulties, with 4 cases excluded due to missing data across all individual difficulties.

least one difficulty at the time of their assessment and on average presented with roughly 2 difficulties ($M = 2.29$, $SD = 1.81$).⁸ Many faced 3 or more difficulties ($n = 287$, 40%), and a sizeable number experienced 5 or more ($n = 106$, 15%). Cumulative difficulties were significantly higher in the Atlantic ($M = 3.47$, $SD = 2.45$) and Western/Northern ($M = 2.80$, $SD = 1.85$) regions, and lower in the Prairies ($M = 2.28$, $SD = 1.73$) and Central Canada ($M = 1.93$, $SD = 1.81$), $F(3, 718) = 7.69$, $p < 0.001$, $\eta^2 = 0.03$. As such, we controlled for region in subsequent analyses.

Diagnostic outcome. Group was a significant predictor for 3 of the 9 difficulties, including employment problems ($p < 0.001$), independent living needs ($p < 0.001$), and housing problems ($p < 0.001$) (Fig. 1). Those with FASD + SFF had significantly higher rates of employment problems (68%), compared to those At Risk for NDD/FASD (5%, $p = 0.035$), and those not diagnosed with FASD (16%, $p < 0.001$), but not compared to those diagnosed with FASD-SFF (42%, $p = 0.212$). Individuals with FASD + SFF also had significantly higher rates of independent living needs (76%) compared to those At Risk for NDD/FASD (45%, $p = 0.029$), and those not diagnosed (49%, $p < 0.001$), but not compared to those diagnosed with FASD-SFF (67%, $p = 0.148$). Individuals with FASD + SFF also had significantly higher rates of housing problems (42%) compared to those not diagnosed (6%, $p < 0.001$), though rates did not differ significantly from those with FASD-SFF (25%, $p = 0.205$), or those At Risk for NDD/FASD (5%, $p = 0.058$).

There were also significant differences between diagnostic groups for cumulative difficulty, $F(3, 716) = 9.50$, $p < 0.001$, $\eta^2 = 0.04$. Post hoc comparisons indicated that the FASD + SFF ($M = 3.07$, $SD = 1.87$) and FASD-SFF groups ($M = 2.45$, $SD = 1.81$) did not significantly differ ($p = 0.555$), while both FASD groups (+/- SFF) had significantly higher cumulative

difficulty scores than the At Risk for NDD/FASD ($M = 1.10$, $SD = 1.26$, $p = 0.004$ for + SFF and $p < 0.00$ for -SFF), and not diagnosed groups ($M = 1.71$, $SD = 1.62$, $p = 0.024$ for + SFF and $p < 0.001$ for -SFF).

Difficulty Profiles Among Those Diagnosed with FASD

Age. Among those diagnosed with FASD, age was a significant predictor for 6 of the 9 difficulties, excluding independent living needs ($p = 0.083$), legal problems with victimization ($p = 0.132$), and legal problems with offending ($p = 0.122$) (Figure 2A). Adolescents had significantly higher rates of school disruption (26%) compared to adults (5%, $p < 0.001$), but not transition-aged youth (18%, $p = 0.091$). Alternatively, adolescents had significantly lower rates of employment problems (20%) compared to transition-aged youth (71%, $p < 0.001$) and adults (79%, $p < 0.001$), as well as significantly lower rates of housing problems (17%) compared to transition-aged youth (36%, $p < 0.001$) and adults (41%, $p < 0.001$). Significantly fewer adolescents were incarcerated (2%) compared to adults (10%, $p = 0.001$) but not compared to transition-aged youth (5% $p = 0.070$). The rate of alcohol misuse in adolescents (33%) was significantly lower than that in adults (51%, $p = 0.003$), but did not significantly differ from transition-aged youth (45%, $p = 0.058$). Substance misuse was also significantly lower in adolescents (41%) compared to both transition-aged youth (57%, $p = 0.012$) and adults (54%, $p = 0.035$).

Cumulative difficulty also differed significantly by age group, $F(2, 517) = 23.48$, $p < 0.001$, $\eta^2 = 0.08$, with significantly higher scores in transition-aged youth ($M = 3.05$, $p = 1.67$) and adults ($M = 3.06$, $p = 1.63$) compared to adolescents ($M = 2.08$, $SD = 1.87$, both $p < 0.001$). Treating age as a continuous predictor of cumulative difficulty *within* each age group indicated a significant positive association for adolescents, $b = 0.49$, $t(275) = 8.52$, $p < 0.001$, $d = 1.03$, 95%

CI [0.37, 0.60], no association for transition-aged youth ($p = 0.824$), and a significant negative association for adults, $b = -0.04$, $t(132) = -2.40$, $p = 0.018$, $d = -0.42$, 95% CI [-0.07, -0.007]. However, this finding should be interpreted with caution as there were very few older adults (e.g., > 50 years) in the sample ($n = 9$).

Living arrangements and age. As might be expected developmentally, living arrangements also varied by age. Compared to both transition-aged youth and adults, a greater proportion of adolescents lived in parent/family placements (i.e., with biological or adoptive parent(s), or in foster care), and a smaller proportion lived independently (Fig. 3A). Living arrangements were broadly distributed for transition-aged youth. Living in a parent/family placement compared to a system/independent placement was associated with fewer individual difficulties for adolescents and adults, but not transition-aged youth. Compared to adolescents living in system/independent placements, those living in parent/family placements had significantly lower rates of legal problems with offending (19% vs. 49%, $p < 0.001$), alcohol misuse (25% vs. 43%, $p = 0.008$) and substance misuse (34% vs. 50%, $p = 0.019$). They also experienced significantly lower levels of cumulative difficulty ($M = 1.75$, $SD = 1.70$, $M = 2.50$, $SD = 1.99$), $F(1, 272) = 13.60$, $p < 0.001$, $\eta^2 = 0.05$. Adults living in parent/family placements vs. system/independent placements also experienced significantly lower rates of legal problems with offending (12% vs. 30%, $p = 0.014$) and substance misuse (38% vs. 61%, $p = 0.016$), but cumulative difficulty did not differ by living placement for adults ($p = 0.085$) (Fig. 3B). Given the increased developmental expectation for independent living among adults, we conducted exploratory analyses in this age band. Not surprisingly, adults with FASD who lived independently compared to those in all other living placements experienced fewer difficulties

related to independent living needs (48% vs. 81%, $p < 0.001$) and housing problems (14% vs. 57%, $p < 0.001$).

Gender. Among individuals diagnosed with FASD, gender was a significant predictor for school disruption, with higher rates in males (23%) compared to females (12%, $p = 0.033$). Legal problems with offending were also significantly higher in males (39%) compared to females (21%, $p < 0.001$) (Figure 2B). Conversely, we found the reverse pattern for incarceration, with significantly higher rates in females compared to males (7% vs. 2%, $p = 0.015$). Gender was not predictive of any other individual difficulty, nor were there significant differences in cumulative difficulty between males ($M = 2.65$, $SD = 1.82$) and females ($M = 2.36$, $SD = 1.83$, $p = 0.107$). Similarly, age group analyses revealed few gender differences for individual difficulties. Among adolescents, gender was a significant predictor for legal problems with victimization, with higher rates in females vs. males (8% vs. 4%, $p = 0.016$). In both transition-aged youth and adults, rates of legal problems with offending were higher in males compared to females (47% males vs. 12% females for transition-aged youth, $p = 0.002$; and 34% males vs. 14% females for adults, $p = 0.016$), whereas rates did not significantly differ for adolescents (37% males vs. 27% females, $p = 0.097$). Gender did not significantly predict differential incarceration rates for any age group, though counts were low for this variable (i.e., only 4% of individuals with FASD experienced this difficulty). Further, cumulative difficulty did not differ by gender for adolescents ($p = 0.461$), transition-aged youth ($p = 0.558$), or adults ($p = 0.068$).

IQ and neurodevelopmental impairment. Individuals with FASD with $IQ < 70$ had significantly higher rates of housing problems (38%) compared to those with IQ in both the 70 to 85 range (20%, $p < 0.001$), and > 85 ranges (9%, $p < 0.001$) (Figure 2C). Those with $IQ < 70$

also had significantly higher rates of alcohol misuse (46%) compared to those with IQ > 85 (29%, $p = 0.030$, but not compared to those with IQ in the 70 to 85 range (36%, $p = 0.060$). Cumulative difficulty also differed significantly by IQ, $F(2, 482) = 6.78$, $p = 0.001$, $\eta p^2 = 0.03$. Those with IQ < 70 had significantly higher cumulative difficulty ($M = 2.85$, $SD = 1.84$) compared to those with IQ in the 70 to 85 range ($M = 2.30$, $SD = 1.82$, $p = 0.006$) and those with IQ > 85 ($M = 2.08$, $SD = 1.70$, $p = 0.018$).

Impairment in 6 of 10 neurodevelopmental domains predicted increased risk for a range of individual difficulties, while language impairment predicted lower risk of employment problems (Fig. 4). Impairment in cognition and adaptive/social functioning was linked with increased risk for the highest number of difficulties, while housing problems was linked with highest number of impaired neurodevelopmental domains, including motor skills, cognition, academic achievement, memory, affect regulation, and adaptive/social functioning. Cumulative neurodevelopmental impairment was also significantly associated with greater cumulative difficulty, $b = 0.26$, $t(518) = 5.72$, $p < 0.001$, $d = 0.50$, 95% CI [0.17, 0.35].

Postnatal trauma. Individuals with FASD who experienced postnatal trauma ($n = 265$, 51%) had significantly higher rates of employment problems (52%) compared to those who had not (39%, $p = 0.015$). The same pattern was evident for housing problems (33% vs. 22%, $p = 0.034$), and legal problems with victimization (8% vs. 2%, $p = 0.015$). Postnatal trauma was also significantly associated with greater cumulative difficulty, $b = 0.45$, $t(518) = 2.80$, $p = 0.005$, $d = 0.25$, 95% CI [0.13, 0.76], with higher average difficulty scores in those with postnatal trauma ($M = 2.77$, $SD = 1.92$) compared to those without ($M = 2.30$, $SD = 1.72$).

Combined models. Results from hierarchical logistic regressions for each individual difficulty, controlling for region in the first block, age and IQ in the second block, and risk

factors (gender, living placement, postnatal trauma, and cumulative neurodevelopmental impairment) in the third block, revealed several significant predictors of individual difficulties in those with FASD (Table 4). Compared to females, males had 2.8 times greater odds of having legal problems with offending, whereas females were 0.3 times more likely to be incarcerated, though a low base rate for this difficulty should be noted. Compared to those living with parent(s) or family, individuals living in system placements or independently had 3.9 times higher odds of having legal problems with offending, 1.9 times higher odds of alcohol misuse, and 1.8 times greater odds of substance misuse. Finally, for each additional neurodevelopmental domain impaired, there was a 1.4-odds increase in employment problems, a 1.4-odds increase in housing problems, and a 1.6-odds increase in legal problems with victimization.

Results from stepwise hierarchical linear regression evaluating the independent contribution of each risk factor on cumulative difficulty, controlling for region in the first block, and age and IQ in the second block, also showed significant risk factors (Table 5). In the final model, region ($p = 0.006$) and age ($p = 0.039$) were significantly associated with cumulative difficulty, but not IQ ($p = 0.566$), and adding risk factors to the third block resulted in a significant increase in the overall predictive model. Gender ($p = 0.037$), living placement ($p < 0.001$), and neurodevelopmental impairment ($p < 0.001$) were each significantly associated with higher cumulative difficulty, but postnatal trauma was not ($p = 0.138$).⁹

Discussion

This study characterized high rates of difficulties in everyday living experienced by a large Canadian cohort of adolescents, transition-aged youth, and adults with PAE assessed for

⁹ Total number of impaired neurodevelopmental domains and IQ were significantly correlated at the bivariate level ($r = -.38, p < .001$). However, model indicators were not suggestive of problematic multicollinearity, and repeating the analyses excluding IQ did not change the overall pattern of results, with comparable adjusted R^2 values (10.9% vs. 11.8%).

387 FASD in Canada, including independent living needs, alcohol and other substance misuse,
388 employment, legal issues with offending, assisted or sheltered housing, and school disruption.
389 For individuals diagnosed with FASD, pertinent risk factors linked with greater experience of
390 individual and cumulative difficulties included age, extremely low IQ, gender, postnatal trauma,
391 living in a system or independent placement (versus with a parent or family member), and
392 overall neurodevelopmental impairment. Many risk factors remained significant predictors of
393 difficulty, even after accounting for the possible contributions of increased developmental
394 opportunity and expectations for independence (age), and global intellectual impairment (IQ).
395 Our findings add to the limited body of empirical evidence demonstrating significant difficulties
396 experienced by adolescents, transition-aged youth, and adults with FASD in key areas, such as
397 housing, education, and employment, underscoring a clear need for substantial supports (Lynch
398 et al., 2015; Streissguth et al., 2004; Temple et al., 2011).

399 Most of our sample (87%) was accessing FASD assessment services for the first time,
400 suggesting high rates of missed early diagnosis during critical developmental years, and lost
401 opportunities for early, focused intervention, all factors that may play a buffering or protective
402 role in shaping positive outcomes (Bobbitt et al., 2016; Streissguth et al., 2004). We found high
403 rates of difficulties among individuals diagnosed with FASD with and without facial features,
404 underscoring concerns that those without overt physical markers associated with PAE may
405 experience additional challenges having their needs recognized, potentially resulting in unequal
406 access to services and worse outcomes. In order to mitigate against risk for adverse outcomes,
407 policy considerations should ensure that individuals at risk of having FASD are identified as
408 early as possible, and in a manner tailored to identifying neurodevelopmental complexity and
409 functional needs over physical markers. Our finding that half of individuals with PAE seen for an

FASD assessment in Canada had experienced postnatal trauma also complements a range of prior studies and reinforces the importance of approaching assessment, care, and everyday supports for people with FASD using a trauma-informed lens (Badry and Wight Felske, 2013; Lebel et al., 2019; McLachlan et al., 2016; Price et al., 2017).

For individuals with FASD, difficulty rates were greater across cohorts with increasing age, with the highest level of cumulative difficulty observed in adults. The adult group was also characterized by a relative “stabilization” from a cross-sectional perspective, and a possible lowering at the oldest end of the age range. This finding complements previous research and recommendations across a range of developmental disabilities supporting the need for early, integrated coordination during the transition from youth to adulthood (Burnside and Fuchs, 2013; Wei et al., 2015; Wilens et al., 2018). By adulthood, relatively few individuals with FASD lived independently (36%). Not surprisingly, these adults had fewer difficulties related to independent living needs and housing problems compared to those with alternative living arrangements. Adults with FASD who are able to achieve independence despite a range of neurodevelopmental and day-to-day obstacles likely represent a group with particular resilience. Further research that focuses on what enables this group to achieve success and overcome risk factors for adverse outcomes would be a valuable contribution to the strengths-based literature on FASD. Additionally, research extending into older adults (e.g., >50 years) with FASD is greatly needed to inform supports for this population as they age.

Rates of employment-related difficulties were notably high for transition-aged youth and impacted the majority of adults with FASD. While the Database does not permit a nuanced evaluation of the nature of these problems, underemployment has been shown to be a major concern for adults with FASD (e.g., Rangmar et al., 2015; Streissguth et al., 1996). With

appropriate supports, individuals with FASD and other complex disabilities who are employed benefit from increased access to financial resources, opportunities for social connection, increased self-esteem and self-worth, and improved quality of life (e.g., Kapasi et al., 2019). As such, our findings underscore the importance of continued consideration of FASD and other neurodevelopmental disabilities in workforce training and policy initiatives.

Individuals with FASD and their families can face challenges accessing community supports in some jurisdictions due to restrictive criteria for services (Petrenko et al., 2014). It is often the case that publicly funded disability services are available only to those with lower overall intellectual ability (typically a standardized IQ score below 70), along with significant deficits in adaptive functioning (Brintnell et al., 2011; Temple et al., 2015). In the current study, adaptive functioning (80%) was the most commonly impaired neurodevelopmental domain, though only half (52%) of the sample had IQ scores below 70. As such, many individuals with significant functional deficits who would likely benefit from coordinated, multi-disciplinary supports for activities of daily living, housing, employment, and mental health/substance use may be excluded from appropriate avenues of service (Brintnell et al., 2011). If individuals with FASD are unable to access developmental sector community supports, it can be difficult for them to fit into other service sectors where their neurodevelopmental challenges may not be well understood or accommodated. Ultimately, this lack of support can result in individuals falling through the cracks of service sectors and experiencing poor outcomes, in addition to substantial stress and strain for caregivers and families (Bobbitt et al., 2016; Paley et al., 2006; Temple et al., 2015).

Our findings are also consistent with research demonstrating increased risk of externalizing problems for boys and men with FASD and other neurodevelopmental disabilities

via elevated rates of school disruption and criminal justice system involvement (e.g., Doyle et al., 2019; Lynch et al., 2015; Streissguth et al., 2004; Theule et al., 2013). However, we also found that relative to the general population, females with FASD had disproportionately higher levels of criminal justice system contact, incarceration, and both alcohol and substance misuse. In terms of alcohol misuse specifically, we found no significant differences between the overall rates reported for males and females with FASD. This is notable because in Canada, males typically experience higher levels of alcohol misuse than females, including more binge drinking (18% of males vs. 13% of females) and chronic drinking (22% vs. 18%) across all age groups from teens to adults (Health Canada, 2016). In addition, the overall rate of alcohol misuse among males and females with PAE in this study (38%) far exceeds Canadian national population estimates (Health Canada, 2016) for both binge drinking (15%) and chronic alcohol use (20%), and extends to 51% of adults diagnosed with FASD. Together, these findings suggest that alcohol misuse is a significant problem for both males and females with FASD, particularly by adulthood, placing them at elevated risk for the associated adverse health and social consequences (World Health Organization, 2014). High rates of alcohol misuse among women with FASD may also put them at increased risk of having an alcohol-exposed pregnancy themselves. Findings highlight the need for targeted prevention efforts, as well as gender-informed approaches to intervention in this area (Gelb and Rutman, 2011; Grant et al., 2014; O'Connor et al., 2016; Poole et al., 2016).

Among the adverse outcomes frequently experienced by individuals with FASD, involvement in the criminal justice system is arguably among the most harmful. One-quarter (26%) of our sample was referred for assessment due to problems with the law, and 15% of referrals came directly from the legal system. Rates of current legal problems with offending

were elevated for individuals with FASD (29 to 31%) compared to rates among youth and adults charged with crimes in Canada (e.g., 1.7 to 1.9% in 2018), and the police-reported crime rate (4 to 6%) (Allen, 2018; Statistics Canada, 2020). These findings suggest high rates of criminal justice system contact for individuals with FASD relative to both the general population and other neurodevelopmental disability populations (e.g., Hellenbach et al., 2017; Lin et al., 2017). That said, our results also fall much below an often earlier cited figure of 60% reported by Streissguth and colleagues and differ in respect to risk profiles (1996; 2004). For instance, low IQ and/or having a diagnosis of FAE (vs. FAS) were protective factors for trouble with the law in Streissguth and colleagues' work. Alternatively, we found comparable rates of legal problems with offending for individuals diagnosed with FASD with and without sentinel facial features, and rates were approximately 10% higher among individuals with IQ < 70 compared to those with higher intellectual functioning. Methodological (e.g., focus on current vs. lifetime adversity) and criminal justice policy differences (e.g., higher incarceration rates in Washington State compared to Canada) are important to consider in interpreting these findings (National Institute of Corrections, 2016; Reitano, 2017). Given the harmful personal and social consequences linked with criminal justice system involvement, particularly for vulnerable populations such as individuals with FASD, further research is needed to inform the evidence base for risk and protective factors, effective prevention policy, and interventions to improve outcomes.

The importance of identifying and building on strengths, resiliencies, and protective factors, for individuals with FASD is being increasingly recognized (Currie et al., 2016; Flannigan et al., 2018; Pei et al., 2016; Rogers et al., 2013). This is necessary not only for informing evidence-based transition and care planning for improved outcomes, but also for helping individuals with FASD to develop and maintain positive, ability-focused self-views, and

502 achieve everyday successes (Flannigan et al., 2018; Sparrow et al., 2013). We found that
503 “system” or independent living placements emerged as a risk factor linked with specific
504 difficulties for both adolescents and adults with FASD. Taken as a mirror image, these findings
505 underscore the protective nature of quality and stable caregiving environments for children with
506 FASD and highlight a window of opportunity for fostering positive outcomes (Streissguth et al.,
507 2004). The Database does not currently consider protective factors or strengths explicitly,
508 suggesting an opportunity for future growth as modifications are made over time.

509 Given that the limited research focusing on adolescents and adults with FASD has
510 primarily emerged from the United States and Europe, it is important to situate the current
511 findings in the Canadian context (e.g., Day et al., 2013; Lynch et al., 2015; Rangmar et al., 2015;
512 Spohr et al., 2007; Streissguth et al., 1991). Canada maintains relatively strong publicly funded
513 health, education, and social service systems and is often considered a leader in FASD-specific
514 policy, research, programming, and prevention initiatives at both regional and national levels
515 (e.g., Cook et al., 2016; Pei et al., 2017; Poole et al., 2016). These factors likely impact the social
516 determinants of health linked with the incidence of PAE and FASD and may differentiate the
517 current difficulty profile relative to other countries. That said, Canada is a geographically broad
518 country with considerable variability in FASD-informed policy and services across regions. As
519 well, there are marginalized groups and communities in Canada who experience compromised
520 social determinants of health that impact an array of adverse health outcomes. In our study, there
521 was an overrepresentation of Indigenous individuals accessing FASD diagnostic services. In
522 Canada, like many places worldwide, Indigenous people continue to recover from the impacts of
523 colonialist policies and experience health inequities driven by social determinants of health
524 (Badry and Wight Feske, 2013; Truth and Reconciliation Commission of Canada, 2015). FASD

occurs in all populations where alcohol is used, and generalizations about prevalence should not be drawn based on these data, particularly given that our sample cannot be considered representative of either the national population or vulnerable subgroups (Wolfson et al., 2019). That said, these findings complement calls for culturally informed and culturally safe FASD services that take into consideration diverse conceptualizations of health and well-being, along with increased efforts to address social determinants of health for everyone in Canada (Rutman et al., 2014; Wolfson et al., 2019).

Limitations. The cross-sectional nature of this study prevents inferences about causality or developmental trajectories, particularly in light of several difficulties being normatively tied to specific developmental periods (e.g., school disruption for adolescents, independent living for adults). As an ongoing clinical data repository, the Database offers a snapshot of current difficulties using categorical indicators, thereby limiting more nuanced evaluation of the timing, severity, and chronicity of challenges. While the Canadian FASD Diagnostic Guideline provides clinicians with a consistent framework to inform assessment and diagnosis, clinicians rely on varied sources of information when conducting evaluations, highlighting the variability in measurement approaches that likely informs Database indicators. For example, difficulties related to alcohol misuse could be informed by informal self-report, record review, or via structured screening or assessment tools. In addition, in situations where an area of difficulty was not assessed, it is impossible to tell why (e.g., clinicians may not have had access to the information; they may not have felt that the problem was relevant and therefore did not investigate). Thus, it is possible that our findings could reflect an underestimate of difficulties, and conclusions cannot be drawn from missing data.

Furthermore, the current findings should not be considered nationally representative given the variable number of clinics participating in the Database within regions, and some geographic areas lacking representation altogether. Difficulty profiles also differed by region, possibly as a result of varied client populations (e.g., children vs. adults), and a few regions being represented by a small number of clinics. Ultimately, based on the large number of cases profiled in this study, our findings suggest important focal points that warrant follow-up using comprehensive longitudinal approaches to best understand and support positive outcomes for individuals with FASD, their caregivers and families, and communities. Adopting a strengths-based approach and involving individuals with FASD and their circles of care, across a wide range of communities, cultures, and settings as stakeholders in future research, are also critical.

Conclusion

This study characterizes high rates of difficulties in everyday living experienced by a large cohort of adolescents, transition-aged youth, and adults with PAE evaluated for FASD in diagnostic clinics across Canada. Future research directions and policy considerations should focus on identifying risk and protective factors at individual and contextual levels that impact well-being and success for individuals with FASD well beyond childhood. Further, policy attention should focus on identifying best practices for ensuring that children, youth, and families impacted by FASD are able to effectively access necessary supports and services required for successful transition to adulthood, and that FASD-informed services are accessible across all of Canada. Importantly, additional research is needed to identify promising and evidence-based interventions and services tailored to adolescents, transition-aged youth, and adults with FASD to support daily living skills and foster positive outcomes.

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Figure Legends

Figure 1. Difficulties experienced by adolescents, transition-aged youth, and adults with PAE, referred for FASD assessment, by diagnostic outcome.

Figure 2. Difficulties experienced by individuals diagnosed with FASD, by age (A), gender (B), and IQ (C).

Figure 3. More adolescents with FASD live with biological parent(s), adoptive parent(s), or other family members, and fewer live independently compared to adults and transition-aged youth, with varied living placements for transition-aged youth (A), and adolescents with FASD living in parent/family placements (biological parent(s), adoptive parent(s), or biological family) have lower cumulative difficulty compared to those living in system/independent placements (foster care, group home, custody, homeless, independent, other), with no differences for transition-aged youth or adults (B).

Figure 4. Neurodevelopmental domains associated with difficulties for adolescents, transition-aged youth, and adults diagnosed with FASD.

Table 1. Evidence of Significant Impairment in Neurodevelopment Domains under the 2016 Canadian FASD Diagnostic Guideline (Cook et al., 2016)

Domain	Evidence for Significant Impairment
Motor Skills	<ul style="list-style-type: none"> • Test score ≤ 2 SD on composite score or multiple subtests of fine motor skills, gross motor skills, graphomotor skills, or visual-motor integration • Tone, reflexes, balance, coordination, strength, and other abnormal findings on the neurological examination also considered
Neuroanatomy/ Neurophysiology	<ul style="list-style-type: none"> • Orbitofrontal head circumferences ≤ 2 SD below the mean • Seizure disorder (not due to known postnatal etiology) • MRI evidence of structural brain abnormality associated with PAE
Cognition	<ul style="list-style-type: none"> • Standardized cognition/intelligence test scores ≤ 2 SD in composite and/or major subdomains • Discrepancy among subdomains (base rate $<3\%$) where lower subdomain score is ≤ 1 SD
Language	<ul style="list-style-type: none"> • Composite score ≤ 2 SD in core, receptive, or expressive language • Multiple subtest scores ≤ 2 SD on higher-level language • Discrepancy among receptive and expressive composites (base rate $<3\%$); lower score is ≤ 1 SD
Academic Achievement	<ul style="list-style-type: none"> • Standardized test scores ≤ 2 SD in reading, math, and/or written language • Discrepancy between cognition and one of the above (base rate $<3\%$) where achievement score ≤ 1 SD
Memory	<ul style="list-style-type: none"> • Composite score ≤ 2 SD in overall, verbal, or visual memory • Discrepancy between verbal and visual (base rate $<3\%$) where lower score is ≤ 1 SD
Attention	<ul style="list-style-type: none"> • Includes sustained/selective attention and resistance to distraction • <i>Direct evidence:</i> Multiple subtest scores ≤ 2 SD in continuous processing or other neuropsychological tests of attention; <i>Indirect evidence:</i> Converging evidence of impairment from multiple sources (interview, questionnaire, record review, observations)
Executive Functioning	<ul style="list-style-type: none"> • Includes working memory, impulse control, hyperactivity, planning/problem-solving, and cognitive flexibility • <i>Direct evidence:</i> Multiple subtest scores ≤ 2 SD in neuropsychological tests of EF; <i>Indirect evidence:</i> Converging evidence from multiple sources (standardized rating scale scores ≤ 2 SD, AND information from interview, record review, observations)
Affect Regulation	<ul style="list-style-type: none"> • DSM-5 criteria for Major Depressive Disorder (with recurrent episodes), Persistent Depressive Disorder, Disruptive Mood Dysregulation Disorder (DMDD), Separation Anxiety Disorder, Selective Mutism, Social Anxiety Disorder, Panic Disorder, Agoraphobia, or Generalized Anxiety Disorder • Long-standing problem vs. response to unfavorable life event

Adaptive/Social
Functioning

- Social communication: *Direct evidence*: standardized scores ≤ 2 SD on social language, social communication, or pragmatic language; direct measures should be used in combination with reports/history
 - Adaptive/social skills: *Indirect evidence*: scores ≤ 2 SD on global composite or major subdomain score based on standardized interview or rating scale; formal direct measures are preferable, but for adolescents/adults without a consistent caregiver in last 2 years, other interview method or file review may be used; where formal measures are not possible, file review is accepted to ascertain: documented history of difficulties with independent living and/or social competence (severity of impairment is determined based on clinical judgment)
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Table 2. Sample Characteristics for Adolescents, Transition-Aged Youth, and Adults with PAE

	Overall sample (<i>N</i> = 726) <i>n</i> (%)	FASD + SFF (<i>n</i> = 73) ^a <i>n</i> (%)	FASD-SFF (<i>n</i> = 452) ^b <i>n</i> (%)	At Risk for NDD/FASD (<i>n</i> = 21) ^c <i>n</i> (%)	Not diagnosed (<i>n</i> = 180) ^d <i>n</i> (%)
Age (<i>M</i> , <i>SD</i>) (<i>n</i> = 726)	19.8 (9.2)	28.1 (12.4)	20.1 (8.8)	14.6 (4.8)	16.5 (6.5)
12 to 17	443 (61)	18 (25)	261 (58)	19 (91)	145 (81)
18 to 24	135 (19)	15 (21)	97 (22)	1 (5)	22 (12)
25 to 60	148 (20)	40 (55)	94 (21)	1 (5)	13 (7)
Gender (% female) (<i>n</i> = 719)	306 (43)	31 (43)	177 (39)	12 (57)	86 (49)
Ethnicity (<i>n</i> = 726)					
Caucasian	194 (27)	22 (30)	113 (25)	7 (33)	52 (29)
Indigenous	377 (52)	44 (60)	241 (53)	12 (57)	80 (44)
Other	29 (4)	3 (4)	21 (5)	0 (0)	5 (3)
Unknown	126 (17)	4 (6)	77 (17)	2 (10)	43 (24)
IQ (<i>n</i> = 668)					
<70	265 (40)	46 (65)	210 (50)	0 (0)	9 (6)
70 to 85	274 (41)	20 (28)	161 (38)	10 (53)	83 (52)
>85	129 (19)	5 (7)	48 (12)	9 (47)	67 (42)
Domains impaired (<i>M</i> , <i>SD</i>) (<i>n</i> = 726)	4.4 (2.3)	6.1 (2.1)	5.3 (1.6)	2.6 (1.2)	1.8 (1.6)
Motor skills (<i>n</i> = 669)	150 (22)	27 (18)	112 (75)	2 (1)	9 (6)
Neuroanatomy/neurophysiology (<i>n</i> = 635)	54 (9)	23 (35)	26 (7)	1 (6)	4 (2)
Cognition (IQ) (<i>n</i> = 703)	399 (57)	56 (78)	314 (72)	6 (30)	23 (13)
Language (<i>n</i> = 687)	231 (34)	34 (53)	168 (39)	3 (15)	26 (15)
Academic achievement (<i>n</i> = 707)	431 (61)	59 (83)	321 (72)	8 (40)	43 (25)
Memory (<i>n</i> = 696)	313 (45)	49 (69)	241 (56)	3 (16)	20 (12)
Attention (<i>n</i> = 697)	415 (60)	41 (62)	294 (68)	13 (68)	67 (38)
Executive function (<i>n</i> = 701)	439 (63)	55 (78)	338 (77)	4 (22)	42 (24)
Affect regulation (<i>n</i> = 672)	303 (45)	38 (60)	225 (53)	4 (22)	36 (21)

Adaptive/social (<i>n</i> = 701)	463 (66)	60 (86)	343 (79)	11 (55)	49 (28)
Living situation (<i>n</i> = 720)					
Independent	86 (12)	14 (19)	56 (13)	1 (5)	15 (8)
Biological parent(s)	136 (19)	13 (18)	82 (18)	5 (24)	36 (20)
Other family	132 (18)	11 (15)	79 (18)	7 (33)	35 (20)
Foster care	121 (17)	3 (4)	65 (15)	5 (24)	48 (27)
Adoptive parent(s)	87 (12)	11 (15)	51 (11)	2 (10)	23 (13)
Group home	44 (6)	2 (3)	32 (7)	0 (0)	10 (6)
Homeless	17 (2)	4 (6)	13 (3)	0 (0)	0 (0)
In custody	38 (5)	3 (4)	29 (7)	0 (0)	6 (3)
Other	59 (8)	12 (16)	40 (9)	1 (5)	6 (3)

Note. FASD, fetal alcohol spectrum disorder; SFF, sentinel facial features; NDD, neurodevelopmental disorder; Indigenous, First Nation, Métis, Inuit; IQ, Intelligence Quotient. %s are calculated based on valid denominator for all variables, *ns* range from 672 to 726 due to missing data. ^a FASD + SFF *n* = 63 to 73. ^b FASD - SFF *n* = 376 to 452. ^c At Risk for NDD/FASD *n* = 18 to 21. ^d Not Diagnosed *n* = 159 to 180. For instance, for IQ < 70, 210 individuals with FASD-SFF from a total of 419 valid cases in the denominator = 50% (rounded).

Table 3. Difficulties in Daily Living Experienced by Adolescents, Transition-Aged Youth, and Adults with PAE Assessed in Canadian Diagnostic Clinics for FASD

	Overall Sample	FASD + SFF (<i>n</i> = 73) ^a	FASD-SFF (<i>n</i> = 452) ^b	At Risk for NDD/FASD (<i>n</i> = 21) ^c	Not Diagnosed (<i>n</i> = 180) ^d
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
School Disruption (<i>n</i> = 649)	116 (18)	9 (14)	78 (20)	4 (19)	25 (15)
Employment Problems (<i>n</i> = 661)	241 (37)	45 (68)	168 (42)	1 (5)	27 (16)
Independent Living Needs (<i>n</i> = 649)	406 (63)	51 (76)	262 (67)	9 (45)	84 (49)
Housing Problems (<i>n</i> = 660)	138 (21)	28 (42)	98 (25)	1 (5)	11 (6)
Legal Problems Victim (<i>n</i> = 686)	30 (4)	7 (10)	17 (4)	0 (0)	6 (3)
Legal Problems Offending (<i>n</i> = 705)	210 (30)	21 (29)	137 (31)	1 (5)	51 (29)
Incarceration (<i>n</i> = 692)	22 (3)	6 (9)	15 (4)	0 (0)	1 (1)
Alcohol Misuse (<i>n</i> = 562)	215 (38)	25 (38)	145 (41)	4 (22)	41 (32)
Substance Misuse (<i>n</i> = 598)	276 (46)	32 (49)	179 (48)	3 (18)	62 (43)

Note. FASD, fetal alcohol spectrum disorder; SFF, sentinel facial features; NDD, neurodevelopmental disorder; PAE, prenatal alcohol exposure. %s are calculated based on valid denominator for all variables, *ns* range from 562 to 705 due to missing data. ^aFASD + SFF *n* = 65 to 72. ^bFASD-SFF *n* = 351 to 436. ^cAt Risk for NDD/FASD *n* = 17 to 21. ^dNot Diagnosed *n* = 127 to 177. For instance, for School Disruption, 78 individuals with FASD-SFF from a total of 396 valid cases in the denominator = 20% (rounded). See Figure 1 for statistical comparison between groups.

Table 4. Hierarchical Logistic Regressions Predicting the Likelihood of Difficulties in Adolescents, Transition-aged Youth, and Adults Diagnosed with FASD

	Cox & Snell R^2	Nagelkerke R^2	B (SE)	Wald	p -value	Odds Ratio	95% CI
School disruption ($n = 423$)							
Gender			0.53 (0.30)	3.11	0.078	1.70	0.94, 3.07
Living placement	13.0%	21.5%	0.21 (0.29)	0.52	0.473	1.23	0.70, 2.19
Postnatal trauma			0.50 (0.29)	2.95	0.086	1.64	0.93, 2.90
ND impairment			0.14 (0.09)	2.14	0.143	1.15	0.95, 1.38
Employment Problems ($n = 432$)							
Gender			0.39 (0.24)	2.57	0.109	1.47	0.92, 2.37
Living placement	28.0%	37.4%	0.16 (0.24)	0.45	0.503	1.18	0.73, 1.90
Postnatal trauma			0.27 (0.24)	1.25	0.263	1.31	0.82, 2.08
ND impairment			0.32 (0.08)	15.49	<0.001	1.38	1.18, 1.62
Independent Living Needs ($n = 421$)							
Gender			0.34 (0.22)	2.39	0.122	1.40	0.91, 2.15
Living placement	5.8%	8.1%	0.23 (0.23)	1.03	0.310	1.26	0.81, 1.97
Postnatal trauma			0.02 (0.22)	0.01	0.936	1.02	0.66, 1.58
ND impairment			0.02 (0.07)	0.06	0.811	1.02	0.88, 1.17
Housing Problems ($n = 427$)							
Gender			0.35 (0.25)	1.99	0.158	1.42	0.87, 2.32
Living placement	16.5%	23.7%	0.21 (0.26)	0.69	0.406	1.24	0.75, 2.05
Postnatal trauma			0.25 (0.25)	0.99	0.319	1.28	0.79, 2.09
ND impairment			0.35 (0.08)	18.30	<0.001	1.42	1.21, 1.66
Legal Problems Victim ($n = 451$)							
Gender			-0.84 (0.51)	2.69	0.101	0.43	0.16, 1.18
Living placement	8.7%	26.1%	0.57 (0.53)	1.14	0.286	1.76	0.62, 4.97
Postnatal trauma			1.04 (0.56)	3.38	0.066	2.81	0.93, 8.48
ND impairment			0.48 (0.17)	7.88	0.005	1.62	1.16, 2.28
Legal Problems Offending ($n = 465$)							
Gender			1.01 (0.23)	18.73	<0.001	2.76	1.74, 4.36
Living placement	14.1%	19.7%	1.35 (0.24)	30.45	<0.001	3.85	2.38, 6.21

Postnatal trauma			-0.06 (0.23)	0.07	0.788	0.94	0.60, 1.47
ND Impairment			0.08 (0.07)	1.12	0.291	1.08	0.94, 1.24
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Incarceration (<i>n</i> = 460) ^a							
Gender			-1.16 (0.51)	5.16	0.023	0.31	0.12, 0.85
Postnatal trauma	4.5%	15.0%	0.22 (0.49)	0.20	0.659	1.24	0.48, 3.23
ND impairment			0.09 (0.16)	0.33	0.568	1.10	0.80, 1.50
<hr/>							
Alcohol Misuse (<i>n</i> = 383)							
Gender			-0.21 (0.22)	0.90	0.34	0.81	0.53, 1.25
Living placement	5.6%	7.5%	0.62 (0.23)	7.46	0.006	1.86	1.19, 2.91
Postnatal trauma			0.01 (0.22)	0.001	0.978	1.01	0.65, 1.56
ND impairment			0.02 (0.07)	0.06	0.807	1.02	0.88, 1.17
<hr/>							
Substance Misuse (<i>n</i> = 404)							
Gender			0.16 (0.21)	0.53	0.468	1.17	0.77, 1.77
Living placement	4.5%	6.0%	0.59 (0.22)	7.47	0.006	1.80	1.18, 2.75
Postnatal trauma			0.31 (0.21)	2.13	0.145	1.36	0.90, 2.06
ND impairment			0.01 (0.07)	0.03	0.872	1.01	0.88, 1.16

Note. ND, Neurodevelopmental; IQ, Intelligence Quotient. For the current analyses, female gender, parent/family living placement, and absence of postnatal trauma were classified as the reference categories. ^aLiving placement was not included as a predictor for incarceration given the confound.

Table 5. Linear Regression Models Predicting Cumulative Difficulties in Adolescents, Transition-aged Youth, and Adults Diagnosed with FASD

	Regression Coefficients ^a			Model Statistics		
	B (SE)	B 95% CI	β (<i>p</i>)	Adj. <i>R</i> ²	TR ²	<i>f</i> ²
Step 1						
Region	0.40 (0.15)	0.11, 0.69	0.12 (0.006)	0.007	0.01 (0.033)	0.009
Step 2						
Age ^b	0.30 (0.14)	0.02, 0.58	0.09 (0.039)	0.04	0.03 (<0.001)	0.04
IQ < 70	-0.08 (0.13)	-0.33, 0.18	-0.03 (0.566)			
Step 3						
Gender	-0.34 (0.16)	0.04, -0.66	-0.09 (0.037)			
Living placement	0.62 (0.17)	0.29, 0.95	0.17 (<0.001)			
Postnatal trauma	0.25 (0.17)	-0.08, 0.57	0.07 (0.138)	0.11	0.08 (<0.001)	0.14
ND impairment	0.23 (0.05)	0.13, 0.33	0.22 (<0.001)			

Note. ND, neurodevelopmental. *N* = 478. Region, IQ < 70, gender, living stability, and postnatal trauma are all categorical variables, while age and ND impairment are continuous (see Methods). ^aRegression coefficients are reported for the final model, and model statistics are reported for each step. ^bAge was included in the model as a squared term owing to nonlinearity and was rescaled for ease of interpretation [(age*sq)/1,000].

Fig. 1. Difficulties experienced by adolescents, transition-aged youth, and adults with PAE, referred for FASD assessment, by diagnostic outcome. %s are calculated based on valid denominators for all difficulties, *ns* range from 562 to 705 due to missing data. FASD+SFF *n* = 65 to 72. FASD-SFF *n* = 351 to 436. At Risk for NDD/FASD *n* = 17 to 21. Not Diagnosed *n* = 127 to 177. For instance, for employment, 168 individuals with FASD-SFF from a total of 403 valid cases in the denominator = 42% (rounded). FASD = fetal alcohol spectrum disorder; SFF = sentinel facial features; NDD = neurodevelopmental disorder. See Table 2 for *n* and % for overall sample.

A. Age

B. Gender

C. IQ

Fig. 2. Difficulties experienced by individuals diagnosed with FASD, by age (A), gender (B), and IQ (C). %s are calculated based on valid denominator for all variables, with ns ranging

across individual difficulties due to missing data, including from 417 to 508 for age, 413 to 504 and gender, and 391 to 473 for IQ. For instance, within panel A, school disruption was positively endorsed for 63 adolescents from a total of 246 valid cases in the denominator = 26% (rounded). *p*-values for individual difficulties for panels A, B, and C are calculated using logistic regression, controlling for region, see text for follow-up analyses for pairwise comparisons. FASD = fetal alcohol spectrum disorder.

Fig 3. More adolescents with FASD live with biological parent(s), adoptive parent(s), or other family members, and fewer live independently compared to adults and transition-aged youth, with varied living placements for transition-aged youth (A), and adolescents with FASD living in parent/family placements (biological parent(s), adoptive parent(s), or biological family) have lower cumulative difficulty compared to those living in system/independent placements (foster care, group home, custody, homeless, independent, other), with no differences for transition-aged youth or adults (B). Percentages are calculated based on valid denominator for all variables. $N = 516$. $n_{\text{adolescents}} = 275$, $n_{\text{transition-aged youth}} = 107$, $n_{\text{adults}} = 134$.

Fig. 4. Neurodevelopmental domains associated with difficulties for adolescents, transition-aged youth, and adults diagnosed with FASD. *N* varies due to missing data for varying combinations of difficulties and neurodevelopmental domains, ranging from *n* = 350 for Alcohol Misuse and Neuroanatomy/Neurophysiology, to *n* = 500 for legal problems with offending and Academic Achievement. Values are regression coefficients from logistic regressions with each individual neurodevelopmental domain as the predictor, for each individual difficulty as the outcome, controlling for region (blue = negative; red = positive). *significant after FDR correction for multiple comparisons ($1/90 \times 0.10 = .001$, Benjamini & Hochberg, 1995, 2000). 1 = Motor Skills; 2 = Neuroanatomy/Neurophysiology; 3 = Cognition; 4 = Language; 5 = Academic Achievement; 6 = Memory; 7 = Attention; 8 = Executive Functioning; 9 = Affect Regulation; 10 = Adaptive/Social Functioning.