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# PREVALENCE OF FETAL ALCOHOL SPECTRUM DISORDER AMONG YOUNG PEOPLE IN YOUTH DETENTION IN WESTERN AUSTRALIA



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# PREVALENCE OF FETAL ALCOHOL SPECTRUM DISORDER AMONG YOUNG PEOPLE IN YOUTH DETENTION IN WESTERN AUSTRALIA

Carol Bower PhD[1,2], Rochelle Watkins PhD[1,2], Raewyn C Mutch FRACP[1,2,3,4], Rhonda Marriott PhD[5], Jacinta Freeman MPH[1], Natalie R Kippin[1], Bernadette Safe BSci(OT)[1,3], Carmela Pestell DPsych[1,6], Candy SC Cheung PhD[6], Helen Shield[6], Lodewicka Tarratt BPsychHons[6], Alex Springall Grad Dip Psych[6], Jasmine Taylor BPsychHons[6], Noni Walker MPH[1], Emma Agiro FRACP[4], Suze Leitão PhD[1,7], Sharynne Hamilton BA(Hons)[1], Carmen Condon MPH[1], Hayley M Passmore BA(Hons)[1,3], Roslyn Giglia PhD[1,2]

[1]Telethon Kids Institute, PO Box 855, West Perth, Western Australia 6872

[2]The University of Western Australia, Perth, Western Australia

[3]School of Paediatrics and Child Health, The University of Western Australia, Perth, Western Australia

[4]Child and Adolescent Health Service, Department of Health Western Australia, Perth, Western Australia

[5]School of Psychology and Exercise Science, Murdoch University, Perth, Western Australia

[6]School of Psychology, The University of Western Australia, Perth, Western Australia

[7] Curtin University, School of Psychology and Speech Pathology, Perth, Western Australia

**Corresponding author**:

Professor Carol Bower

Telethon Kids Institute

PO Box 855, WEST PERTH WA 6872, Australia

Telephone: +618 9489 7751

Email: carol.bower@telethonkids.org.au

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**ABSTRACT**

**Objectives:** To estimate the prevalence of Fetal Alcohol Spectrum Disorder (FASD) among young people in youth detention in Australia. Neurodevelopmental impairments due to FASD can predispose young people to engagement with the law. Canadian studies identified FASD in 11 - 23% of young people in corrective services but there are no data for Australia.

**Design:** Multidisciplinary assessment of all young people aged 10 years to 17 years 11 months and sentenced to detention in the only youth detention centre in Western Australia, from May 2015 to December 2016. FASD was diagnosed according to the Australian Guide to the Diagnosis of FASD.

**Participants:** 99 young people completed a full assessment (88% of those consented; 60% of the 166 approached to participate); 93% were male and 74% were Aboriginal.

**Findings:** 88 young people (89%) had at least one domain of severe neurodevelopmental impairment, and 36 were diagnosed with FASD, a prevalence of 36% (95% confidence interval 27% – 46%).

**Conclusions:** This study, in a representative sample of young people in detention in Western Australia, has documented a high prevalence of FASD and severe neurodevelopmental impairment, the majority of which had not been previously identified. These findings highlight the vulnerability of young people within the justice system and their significant need for improved diagnosis to identify their strengths and difficulties, and to guide and improve their rehabilitation.

**Strengths and limitations of this study:**

- Study conducted in the only youth detention centre in the Western Australia
- Representative sample of young people in detention in Western Australia
- Comprehensive, multidisciplinary assessment, using Australian diagnostic criteria for FASD
- Inability to obtain information on prenatal alcohol exposure for some young people
- Did not assess the domain of affect regulation and limited assessment of domain of adaptive behaviour for some young people

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## INTRODUCTION

Fetal Alcohol Spectrum Disorder (FASD) is characterised by severe, pervasive neurodevelopmental impairment due to prenatal alcohol exposure. Impairment in executive function, memory, language, learning and attention in young people with FASD can result in a range of difficulties including understanding cause and effect, learning from past experiences and decision making. These impairments can, in turn, lead and contribute to problems at school and with employment, mental health, social exclusion, substance misuse and early and repeated engagement with the law. In a University of Washington study of 415 patients with Fetal Alcohol Syndrome or Fetal Alcohol Effects (median age at follow-up was 14 years of age), 60% had been in trouble with the law and 35% had been incarcerated for a crime[1].

There are limited data on the prevalence of FASD among young people in correctional systems. A systematic review published in 2011[2] identified three studies, all from Canada[3-5] and a more recent systematic review [6] identified one additional Canadian study.[7] Only one of these studies involved active case ascertainment using clinical assessment to identify FASD among 287 youth remanded to a forensic psychiatric assessment unit[3]. One sought mention of FASD in the records of 230 youth attending a sexual offender treatment program [5] and the other two obtained information on FASD by self-report in a survey of youth in custody.[4,7] The identified prevalence of FASD was 10.9%,[5] 11.7%,[4] 21% [7] and 23.3%[3], although the number of cases of undiagnosed FASD in custodial and correctional systems was thought to be high.

There is increasing concern regarding the forensic implications of FASD in Australia[8,9], as the neuropsychological sequelae can affect all aspects of the legal proceedings, including the person understanding the expectations and providing credible evidence in forensic interviews, fitness to plead, capacity to stand trial and the process of sentencing.[9,10] There are no data on the prevalence

of FASD in the justice system in Australia, but it is well-recognised that FASD is under-diagnosed in the general population,[11,12] and a high prevalence of intellectual disability and poor mental health has been identified amongst young people in the justice system. In a study of 65% of young people in eight juvenile justice centres in New South Wales (n=295), 45.8% had borderline or lower intellectual functioning, including 14% with an IQ < 70.[13] Additionally, in a survey of 273 young people serving custodial orders in Victoria, 39% had depressive symptoms, 17% had a positive psychosis screen and 22% had engaged in deliberate self-harm in the past six months.[14] These findings highlight the possibility of undiagnosed FASD amongst these young people.

Based on currently available data, FASD is diagnosed more commonly and at higher rates in Aboriginal compared with non-Aboriginal children in Australia.[15-17] Of concern, Aboriginal young people are over 20 times more likely to be in detention compared with non-Aboriginal young people in Australia[18] and, in Western Australia between 2015 and 2016, 73% of youth in detention were Aboriginal.[19]

We report here a study to assess the prevalence of FASD among young people in youth detention in Western Australia.

**Methods**

A paper describing the full study protocol has been published[20]and is summarised here.

**Setting**

We conducted the study between May 2015 and December 2016, in the Banksia Hill Detention Centre (BHDC), the only youth detention centre in Western Australia. Males and females (94% male), aged 10 to 18 years, reside at the Centre either on remand or sentenced to detention, and 73% are Aboriginal.[19]

**Ethics and Governance**

Ethics approval was given by the Western Australian Aboriginal Health Ethics Committee (approval number 582) and the University of Western Australia Human Research Ethics Committee (approval number RA/4/1/7116). The former Department of Corrective Services granted research approval (DCS; project ID 335). The Department for Child Protection and Family Support (DCPFS) also gave approval for the research to include young people in their care (approval number 2015/8981).

A Consumer and Community Reference Group, a Steering Group, and a Reference Group of DCS and DCPFS representatives, provided advice and guidance to the research team.

**Participants**

All young people sentenced to detention within BHDC, aged 10-17 years 11 months were eligible to participate. To allow sufficient time for completion of the assessment, only those young people with at least two further weeks of detention from the time they were invited to participate were included.

**Recruitment**

Participants were recruited by a face to face approach from the project research officer, who identified eligible young people from the Centre census each week, up to a maximum of four per week (the capacity of the assessment team, given assessments were restricted to only two days per week). If a young person expressed interest in being involved in the study, the research officer explained the purpose of the study using simple language and pictorial information sheets and assent forms. When a young person gave assent, written consent was then sought from their identified responsible adult or, in the case of young people in the care of DCPFS, consent was sought directly from the DCPFS case manager responsible for that young person.

**Data collection**

The research officer used standardised forms to collect and record information from the participant (psychosocial checklist), the responsible adult or the child protection case managers (background history, prenatal alcohol exposure, adaptive behaviour, executive functioning), detention centre teachers (adaptive behaviour, executive functioning) and youth custodial officers (adaptive behaviour, social skills, social communication).

The Alcohol Use Disorders Identification Test – Consumption (AUDIT-C)[21] questions were used to assess prenatal alcohol exposure if the young person's birth mother was their responsible adult. When this was not possible, other evidence of exposure was sought from the responsible adult, such as observation of alcohol use during pregnancy. Prenatal alcohol exposure was categorised according to the Australian Guide to the Diagnosis of FASD[22] as: (i) no exposure, if there was confirmed absence of prenatal alcohol; (ii) confirmed exposure, if the AUDIT-C score was 1-4, or there was confirmed use but the level of exposure was not known; (iii) confirmed high risk exposure, if the AUDIT-C score was 5+ or it was reliably known that exposure was at a high level (such as consumption of 5 or more standard drinks on at least one occasion in pregnancy); or (iv) unknown exposure, if there was no or inconsistent information on whether there was prenatal alcohol exposure.

**Clinical assessments**

A multidisciplinary team (paediatrician, occupational therapist, speech pathologist, provisional neuropsychologists with supervision) conducted the clinical assessment, blind to information on prenatal alcohol exposure. For participants who spoke English as an additional language, language assessment was conducted informally by the speech pathologist working in collaboration with accredited interpreters. Table 1 lists the assessment tools used by the clinicians. On completion of the assessment, the multidisciplinary team met to review the findings and consider any diagnoses, taking into account cultural background, lived trauma and disrupted attachment, schooling history and co-occurring morbidities such as attention-deficit/hyperactivity disorder, intellectual disability.

The team prepared a report for every participant, which detailed the results of the assessments and recommendations for supporting and working with the young person, using the young person's identified strengths. This report not only served to establish a baseline to monitor progress, but also provided guidance regarding health and medical needs, the development of appropriate educational or occupational goals, factors to consider for interventions, compensatory strategies and overall case management. When possible, members of the research team discussed the report with the young person using simple verbal feedback combined with simple visual aids as needed. The young person received a paper copy of the report upon release from detention. The reports were also provided to the young person's responsible adult and, with consent, to staff in youth justice services (including health and psychological services), lawyers and other agencies as indicated.

**Diagnostic Criteria**

We used the criteria contained in the Australian Guide to the Diagnosis of FASD (Table 2).[22] These criteria only came into effect after the study protocol was designed and, as Affect Regulation was added as a domain of neurodevelopmental impairment in the new criteria, this domain was not formally assessed in this study.

**Pilot study**

We conducted a pilot study in May 2015 with 11 young people. As only minor modifications were made to the processes for enrolment and assessment based on the pilot study, these 11 cases were included in the full study, which ran until December 2016.

**Statistical methods**

Descriptive analyses were conducted using IBM SPSS Statistics for Windows, Version 24, Armonk, NY, USA, released 2016.

**Role of the funding sources**

The funders had no role in the study design, data collection, analysis, interpretation of the data, writing the paper or in the decision to submit the paper for publication. The authors have not been paid to write this article by a pharmaceutical company or other agency. The corresponding author (Carol Bower) had full access to all the data in the study and had final responsibility for the decision to submit for publication.

## RESULTS

### Participation

Between May 2015 and December 2016, 213 young people were identified as eligible for inclusion, however, 47 were not approached due to our inability to undertake more than four assessments per week. Of those approached, 154 young people assented to participate (93%) and 12 young people declined. Of the 154 assenting young people, the responsible adult for 113 of them gave written consent for their participation (73%). Consent was declined for 3 young people, 10 responsible adults gave verbal but not written consent (written consent was a requirement of the study), 14 young people either turned 18 or were released before written consent was obtained, and we were unable to contact the responsible adult for the remaining 14 young people, despite repeated attempts. Following assent and consent, five young people were released before assessment. The remaining 108 underwent assessment (96% of those consented); 99 of whom completed a full assessment (88% of those consented; 60% of the 166 approached to participate).

### Characteristics of participants

The majority of young people with a completed assessment were male (92; 93%) and Aboriginal (73; 74%), and a third were aged 17 years (Table 3). The responsible adult for most young people

assessed was a parent (62; 63%), 24 (24%) had another person as their guardian (frequently a grandmother), and 13 (13%) were in the care of the DCPFS. Half the young people lived in the metropolitan area. There were no significant differences between these proportions and those for young people assented but not consented (Table 3).

**Diagnosis of FASD**

A total of 36 young people were diagnosed with FASD, a prevalence of 36% (95% confidence interval 27% – 46%). All diagnoses were in the category of FASD with < 3 sentinel facial features; two were non-Aboriginal (FASD prevalence=8%), 34 were Aboriginal (FASD prevalence=49%). Two young people had a FASD diagnosis prior to entering the study. One was diagnosed 5-6 years previously and one was a more recent diagnosis but had not had all domains assessed at that time. Both young people had the diagnosis of FASD confirmed using the new Australian criteria.[22]

**Prenatal alcohol exposure (Table 4)**

Prenatal alcohol exposure amongst fully assessed young people was confirmed for 47 (47%), 28 (28%) of whom had documented high level exposure. Prenatal exposure was unknown for 13 young people (13%) and 39 were confirmed as not exposed to prenatal alcohol (39%).

**Neurodevelopmental domains with severe impairment**

Eleven of the fully assessed young people had no domains of severe neurodevelopmental impairment (11%), 23 had one or two domains severely impaired and the remaining 65 had three or more domains severely impaired (Table 5). Just over half the young people diagnosed with FASD had three or four domains severely impaired, the remainder had five or more severely impaired domains. The individual domains that were severely impaired are shown in Table 6. The majority of young people with FASD had severe impairment in the academic (86%), attention (72%), executive

functioning (78%) and/or language (69%) domains. Severe impairment in memory (56%), motor skills (50%) and cognition (36%) were also commonly found in the young people with FASD. Severe impairment in these domains was also seen amongst the young people without a FASD diagnosis, but at lower levels. Only one young person (who did not have FASD) was identified with a severe impairment in the brain structure/neurology domain.

We intended to assess the adaptive functioning/social skills/social communication domain using the Vineland Adaptive Behaviour Scales – parent/caregiver rated and teacher rated forms,[23,24] the Life Skills Checklist and an informal social skills and communication questionnaire.[25] However, this was not possible for 81 young people. Reasons included informants not knowing the participants for long enough, and non-return or incomplete forms. .

Overall, 25 young people (25%) were assessed to have an IQ score below 70, using the WASI-II or WNV;[26,27] ten without FASD (16%) and 15 with FASD (42%).

Of the 13 young people with unknown prenatal alcohol exposure, there were nine with three or more severely impaired domains. Among eight young people with known exposure to prenatal alcohol who did not have a FASD diagnosis but whose adaptive functioning/social skills/social communication domain had not been assessed, four had two domains meeting severe impairment. Hence, for these four and the nine with unknown prenatal alcohol exposure and three affected domains, a diagnosis of FASD is possible.

**Sentinel facial features**

The majority of young people (73; 74%) had no characteristic facial features of FASD and none had all three facial features (Table 6). One young person (without FASD) had a palpebral fissure length <= 2 standard deviations, 19 had a lip philtrum rank 4 or 5 (13 of whom had FASD), and 18 had an upper lip rank 4 or 5 (8 with FASD).

**DISCUSSION**

This is the first study to estimate the prevalence of FASD in youth detention in Australia. We found that 36% of 99 young people aged 13-17 years were diagnosed with FASD. Study diagnoses were made according to the Australian diagnostic criteria[22] - all cases received a diagnosis of FASD with less than 3 sentinel facial features. This is the highest reported prevalence of FASD in a youth justice setting world-wide. There are four other studies (all from Canada[3-5,7] with FASD prevalence ranging from 10.9% to 23.3%, all outside the lower 95% confidence interval of this study's estimate. Only one of these studies clinically assessed young people to make the diagnosis,[3] while the others used self-report or record review to identify cases and differing criteria for inclusion as a FASD. Hence they may underestimate the true prevalence, although two of these studies were in special groups (sexual offenders,[5] young people in a psychiatric unit[3]) in which FASD may be more common.

However, for several reasons, our prevalence of 36% may also be an underestimate. First, we did not formally assess the domain of affect regulation, and self-reported mental health problems are common among youth in custody in Australia.[13,14] The affect regulation domain was included for the first time in the new Canadian guidelines for FASD diagnosis[28] and the Australian Diagnostic Guide,[22] both of which were published after our study had started. Second, we estimate that a possible further four cases of FASD may have been identified had we been able to formally assess the adaptive functioning/social skills/social communication domain and found it impaired in young people with prenatal alcohol exposure and two other impaired domains. This was not possible

because we were unable to obtain formal measures of adaptive functioning for the majority of young people although, informally, the fact of being in detention suggests impaired adaptive functioning. Third, we were not able to determine whether there had been prenatal alcohol exposure for 13 young people and, of these, nine had three or more domains of impairment, so they may also have met the diagnostic criteria had they been exposed to alcohol prenatally. Fourth, the brain structure/neurology domain was only assessed clinically - no neuro-imaging was undertaken, so impairment in this domain may also be underestimated.

Given the known high risk of young people with FASD engaging with the law[1] it is not surprising that, in this study, the overall prevalence of FASD is almost twice that of the highest population estimate of FASD in Australia of 19%, reported in a remote, mainly Aboriginal, population of 7-8 year olds.[16] Furthermore, the prevalence of severe neurodevelopmental impairment in our study is almost three times as high as the 31% found in the study of Fitzpatrick et al.[17] In the Canadian studies, FASD prevalence in Aboriginal youth ranged from 19% to 36%,[4,5,7] compared with 49% in our study. Corresponding prevalence in non-Aboriginal youth ranged from 4-6%, similar to our study of 8%, and much higher than general population estimates in Western Australia.[29]

Our study has several strengths. It was conducted in the only youth detention facility in Western Australia, and there was a high level of engagement in the study – 93% of the young people approached gave assent and 73% of their responsible adults gave written consent for participation. The age, sex and ethnic profile of the sample was similar to all young people in BHDC at the time of the study.[19] Thus the sample is likely to be representative of all young people in detention in WA.

A further positive feature of the study was the assessment, by a multidisciplinary team, of 9 neurodevelopmental domains and the development of a report specific to each young person. The report included recommendations for working with the young person based on their strengths and

areas of difficulty, and feedback was given to the young people, their responsible adults, detention centre and other youth justice staff and staff from other relevant agencies, to help guide their management while in detention and upon release.

This assessment also identified a high level of severe neurodevelopmental impairment in participants, with only 11% of young people without at least one domain of severe neurodevelopmental impairment, regardless of a diagnosis of FASD. Twenty-five young people (25%) were assessed to have an IQ score < 70, higher than the 14% found in the study of young people in custody in New South Wales [13] and much higher than in the general population in Western Australia (1.7% overall; 3.9% in Aboriginal children). [30] Only two young people had been diagnosed with FASD prior to participation in this study, similar to the study of Fast et al,[3] where only three of 67 cases of FASD had been previously diagnosed. For many of these young people, this was the first time they had received a comprehensive assessment to examine their strengths and difficulties, despite attending school and, in many cases, prior engagement with child protection services and the justice system. These are missed opportunities for earlier diagnosis and intervention, which may have prevented or mitigated their involvement with justice services.

Youth Justice Services in Western Australia are responsible for the safety, security and rehabilitation of young people in custody and young people engaged with these services in the community (http://www.correctiveservices.wa.gov.au/youth-justice/default.aspx; accessed 30 Aug 2017). Given our findings of a high prevalence of FASD and neurodevelopmental impairment among youth in detention, understanding a young person's developmental difficulties and relative strengths provides a sound basis on which to tailor appropriate rehabilitation.

**Conclusions**

This study, in a representative sample of young people in detention in Western Australia, has documented a high prevalence of FASD and severe neurodevelopmental impairment, the majority of

which had not been previously identified. These findings highlight the vulnerability of young people within the justice system and their significant need for improved diagnosis to identify their strengths and difficulties, and to guide and improve their rehabilitation.

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**Declaration of interests**

The authors declare no conflicts of interest.

**Contribution of the authors**

Carol Bower: literature search, study design, collaboration with stakeholders, data analysis, data interpretation, writing first draft

Rochelle Watkins: literature search, study design, collaboration with stakeholders, data interpretation, writing

Raewyn Mutch: study design, collaboration with stakeholders, clinical assessments, data collection, data interpretation, writing

Rhonda Marriott: collaboration with stakeholders, cultural guidance

Jacinta Freeman: study design, collaboration with stakeholders, project management, data interpretation

Natalie Kippin: study design, collaboration with stakeholders, clinical assessments, data collection, data interpretation, writing

Bernadette Safe: study design, collaboration with stakeholders, clinical assessments, data collection, data interpretation, writing

Carmela Pestell: study design, supervision of provisional neuropsychologists, data interpretation, writing

Candy SC Cheung: study design, clinical assessments, data collection, data interpretation

Helen Shield: clinical assessments, data collection, data checking, data interpretation

Lodewicka Tarratt: clinical assessments, data collection, data interpretation

Alex Springall: clinical assessments, collaboration with stakeholders, data collection, data interpretation

Jasmine Taylor: clinical assessments, data collection, data interpretation

Noni Walker: collaboration with stakeholders, project management, data interpretation

Emma Agiro: clinical assessments, data collection, data checking, data interpretation

Suze Leitão: professional support to speech pathologist, collaboration with stakeholders, data interpretation, writing

Sharynne Hamilton: collaboration with stakeholders, cultural guidance, data interpretation

Carmen Condon: data management, data checking, data analysis, data interpretation

Hayley Passmore: collaboration with stakeholders, data interpretation, writing

Roslyn Giglia: study design, collaboration with stakeholders, project management, data interpretation

All authors read and had the opportunity to contribute to drafts of the paper. All authors approve the final paper.

**Table 1. Diagnostic assessments used by multidisciplinary diagnostic team**

| Clinician | Assessment | |
|---|---|---|
| **Paediatrician** | Medical assessment (including measurement of palpebral fissure length, lip philtrum and upper lip volume using UW Lip-Philtrum Guides 1 and 2[31] and structured interview considering early life, educational opportunity, lived trauma and additional risk factors for neurocognitive impairment including high risk behaviours such as early onset and frequent substance, high impact head injury or post-traumatic stress disorder[32-34] | |
| **Neuropsychologist** | Wechsler Abbreviated Scale of Intelligence – Second Edition (WASI-II)[26]<br>Wechsler Non-Verbal Test of Intelligence (WNV)[27] including spatial span*<br>Delis-Kaplan Executive Function System for colour-word interference, trail making and category fluency[35]<br>Wide Range Achievement in Memory & Learning – Second Edition (WRAML-II) Screening Memory Index[36]<br>Wide Range Achievement Test – Fourth Edition (WRAT-4) for reading comprehension, word reading, sentence comprehension, spelling and math computation[37] | |
| **Speech Pathologist** | **Speakers of Standard Australian English and Australian Aboriginal English:** | **Speakers of an Aboriginal Language:** |
| | Clinical Evaluation of Language Fundamentals, Fourth Edition, Australian Standardised Edition(CELF-4 Australian)[38] ᵗ<br>Comprehensive Test of Phonological Processing – Second Edition[40]<br>Informal narrative task (oral and written), measuring sequence and grammar in connected discourse (based on Snow and Powell[41]) | Informal non-word repetition task measuring phonological working memory and phonological awareness (adapted from Gould[39])<br>Informal story recall task<br>Informal receptive grammar task<br>Informal vocabulary and word classes task<br>Picture description barrier game task measuring sentence-level vocabulary and prepositions, self-monitoring and response to prompting<br>Informal narrative task (oral and written) with inferencing and predictive tasks<br>Clinical Evaluation of Language Fundamentals, Fourth Edition, Screening Test Australian & New Zealand Language Adapted Edition (CELF-4 Screener)[42] to gauge standard Australian English competence |
| | Informal oromotor, articulation, phonology and motor speech assessments | |
| **Occupational Therapist** | Beery Visual Motor Integration including Motor Coordination and Visual Perception subtests[43]<br>Movement Assessment Battery for Children- Second Edition (Movement ABC-2)[44]<br>Quick Neurological Screening Test Third Edition[45]<br>Informal handwriting screen<br>Sensory Profile- Adolescent/Adult Self Questionnaire[46]<br>Vineland Adaptive Behaviour Scales for review of motor and daily living skills domain[23,24] | |

*WNV administered instead of the WASI if participant could not speak fluent Australian English.

ᵗ For speakers of Aboriginal Australian English, responses were coded in standard Australian English, and with aspects of Australian Aboriginal English grammar based on literature including Pearce and Williams.[47]

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**Table 2. Australian diagnostic criteria and categories for Fetal Alcohol Spectrum Disorder[22]**

| Diagnostic criteria | Diagnostic categories | |
|---|---|---|
| | FASD with 3 Sentinel Facial Features | FASD with < 3 Sentinel Facial Features |
| Prenatal alcohol exposure | Confirmed or unknown | Confirmed |
| Neurodevelopmental domains<br>- Brain structure/Neurology<br>- Motor Skills<br>- Cognition<br>- Language<br>- Academic Achievement<br>- Memory<br>- Attention<br>- Executive Function, including impulse control and hyperactivity<br>- Affect Regulation<br>- Adaptive Behaviour, Social Skills or Social Communication | Severe impairment* in at least 3 neurodevelopmental domains | Severe impairment* in at least 3 neurodevelopmental domains |
| Sentinel facial features<br>- Short palpebral fissure<br>- Smooth philtrum<br>- Thin upper lip | Presence of 3 sentinel facial features | Presence of 0, 1 or 2 sentinel facial features |

* Severe impairment is defined as either a global score or a major subdomain score on a standardised validated neurodevelopmental scale that is ≤2 SD below the mean or < 3rd percentile.

**Table 3. Demographic characteristics of young people who completed the full FASD assessment compared with those assenting but written consent not obtained.**

| | Completed assessment (N=99) N (%) | Assented but not consented (N=41) N (%) | |
|---|---|---|---|
| **Gender*** | | | |
| Male | 92 (93) | 40 (98) | Fisher's Exact P=0.7 |
| Female | 6 (6) | 1 (2) | |
| **Age in years** | | | $\chi^2$ = 0.5; P= 0.97 |
| 17 | 33 (33) | 15 (37) | |
| 16 | 23 (23) | 10 (24) | |
| 15 | 23 (23) | 9 (22) | |
| 14 | 16 (16) | 5 (12) | |
| 13 | 4 (4) | 2 (5) | |
| **Ethnicity** | | | |
| Australian non-Aboriginal | 16 (16) | 9 (22) | $\chi^2$ = 1.5; P= 0.5 |
| Australian Aboriginal | 73 (74) | 30 (73) | |
| Other** | 10 (10) | 2 (5) | |
| **Place of residence** | | | |
| Metropolitan | 50 (51) | 22 (54) | $\chi^2$ = 0.1; P= 0.7 |
| Rural/Regional/Remote | 49 (49) | 19 (46) | |
| **Legal guardian** | | | |
| Parent | 62 (63) | 24 (58) | $\chi^2$ = 3.5; P= 0.2 |
| Guardian | 24 (24) | 15 (37) | |
| Child protection^ | 13 (13) | 2 (5) | |

* includes those who identify as transgender; ** includes young people of New Zealand, Asian, African ethnicity; ^ Child Protection and Family Support Services

**Table 4. Prenatal alcohol exposure for all young people completing the full FASD assessment**

| **Prenatal alcohol exposure** | **Total completing FASD assessment (N=99) N (%)** | **Diagnosed with FASD (N=36) N (%)** | **Not diagnosed with FASD (N=63) N (%)** |
|---|---|---|---|
| Confirmed | 47 (47) | 36 (100) | 11 (17) |
| *Confirmed high risk* | *28 (28)* | *22 (61)* | *6 (10)* |
| No exposure | 39 (39) | 0 | 39 (62) |
| Exposure unknown | 13 (13) | 0 | 13 (21) |

**Table 5. Total number of severely impaired neurodevelopmental domains amongst all young people completing the full FASD assessment.**

| Number of domains severely impaired | Total completing FASD assessment (N=99) N (%) | Diagnosed with FASD (N=36) N (%) | Not diagnosed with FASD (N=63) N (%) |
|---|---|---|---|
| 0 | 11 (11) | 0 | 11 (17) |
| 1 | 13 (13) | 0 | 13 (21) |
| 2 | 10 (10) | 0 | 10 (16) |
| 3 | 26 (26) | 9 (25) | 17 (27) |
| 4 | 16 (16) | 12 (33) | 4 (6) |
| 5 | 11 (11) | 5 (14) | 6 (10) |
| 6 | 6 (6) | 5 (14) | 1 (2) |
| 7 | 6 (6) | 5 (14) | 1 (2) |
| 8 | 0 | 0 | 0 |
| 9 | 0 | 0 | 0 |

**Table 6. Diagnostic features of young people completing full FASD assessment**

| | Not diagnosed with FASD N=63 | Diagnosed with FASD N=36 |
|---|---|---|
| | N (%) | N (%) |
| **Neurodevelopmental domains impaired*** | | |
| Academic achievement | 30 (48) | 31 (86) |
| Attention | 28 (44) | 26 (72) |
| Executive function | 25 (40) | 28 (78) |
| Language | 20 (32) | 25 (69) |
| Memory | 18 (29) | 20 (56) |
| Motor skills | 11 (17) | 18 (50) |
| Cognition | 8 (13) | 13 (36) |
| Adaptive functioning/social skills/social communication** | 2 (3) | 4 (11) |
| Brain structure/neurology | 1 (2) | 0 |
| **Number of sentinel facial features** | | |
| 0 | 52 (83) | 21 (58) |
| 1 | 5 (8) | 9 (25) |
| 2 | 6 (9) | 6 (17) |
| 3 | 0 | 0 |

* Domains according to the Australian Guide to the Diagnosis of FASD, excluding Affect Regulation[22]

** 29 young people with FASD and 52 without FASD did not have this domain assessed.

**REFERENCES**

1. Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics* 2004; **25**(4): 228-38.
2. Popova S, Lange S, Bekmuradov D, Mihic A, Rehm J. Fetal alcohol spectrum disorder prevalence estimates in correctional systems: A systematic literature review. *Canadian Journal of Public Health* 2011; **102**(5): 336-40.
3. Fast DK, Conry J, Loock CA. Identifying fetal alcohol syndrome among youth in the criminal justice system. *Journal of Developmental and Behavioral Pediatrics* 1999; **20**(5): 370-2.
4. Murphy A, Chittenden M, . Time Out II: A Profile of BC Youth in Custody. Vancouver, 2005.
5. Rojas E, Gretton HM. Background, offence characteristics, and criminal outcomes of Aboriginal youth who sexually offend: a closer look at Aboriginal youth intervention needs. *Sex Abuse* 2007; **19**: 257-83.
6. Hughes N, Clasby B, Chitsabesan P, Williams H. A systematic review of th prevalence of foetal alcohol syndrome disorders among young people in the criminal justice system. *Cogent Psychology* 2016; **3**: 1-8.
7. Smith A, Cox K, Poon C, Stewart D. Time out III:A profile of BC youth in custody. Vancouver, 2013.
8. Douglas H, Hammill J, Hall W, Russell EA. Judicial views of foetal alcohol spectrum disorder in Queensland's criminal justice system. *Journal of Judicial Administration* 2012; **21**(3): 178-88.
9. Freckleton I. Sentencing offenders with foetal alcohol spectrum disorder (FASD): the challenge of effective managment. *Psychiatry, Psychology and Law* 2016; **23**(6).
10. Children's Court of Western Australia. The state of Western Australia -v-BB. Perth; 2015.
11. Payne JM, France KE, Henley N, et al. Paediatricians' knowledge, attitudes and practice following provision of educational resources about prevention of prenatal alcohol exposure and Fetal Alcohol Spectrum Disorder. *Journal of paediatrics and child health* 2011; **47**(10): 704-10.
12. Elliott EJ, Payne J, Morris A, Haan E, Bower C. Fetal alcohol syndrome: a prospective national surveillance study. *Archives of disease in childhood* 2008; **93**(9): 732-7.
13. Haysom L, Indig D, Moore E, Gaskin C. Intellectual disablity in young peope in custody in New South Walse, Australia - prevalence and markers. *Journal of Intellectual Disability Research* 2914; **doi:101111/jir.12109**.
14. Kinner SA, Degenhardt L, Coffey C, Sawyer S, Hearps S, Patton G. Complex health needs in the youth justice system: a survey of community-based and custodial offenders. *Journal of Adolescent Health* 2014; **54**: 521-6.
15. Mutch RC, Watkins R, Bower C. Fetal alcohol spectrum disorders: Notifications to the Western Australian Register of Developmental Anomalies. *Journal of paediatrics and child health* 2014; **51**(4): 433-6.
16. Fitzpatrick JP, Latimer J, Carter M, et al. Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: the Lililwan Project. *Journal of paediatrics and child health* 2015; **51**(4): 450-7.
17. Fitzpatrick JP. Neurodevelopmental outcomes and fetal alcohol spectrum disorders (FASD) in remote Australian Aboriginal children: The Lililwan Project. Sydney, NSW: University of Sydney; 2015.
18. Australian Institute of Health and Welfare. Youth detention population in Australia 2016. Canberra: Australian Government, 2016.
19. Department of Corrective Services. 2015-2016 Annual Report, Department of Corrective Services, Government of Western Australia

2016. http://www.correctiveservices.wa.gov.au/about-us/statistics-publications/dcs-annual-report.aspx (accessed 17 July 2017.

20. Passmore HM, Giglia R, Watkins RE, et al. Study protocol for screening and diagnosis of fetal alcohol spectrum disorders (FASD) among young people sentenced to detention in Western Australia. *BMJ Open* 2016; **6**(6): e012184.
21. Bush K, Kivlahan DR, McDonell MB, Fihn SD, Bradley KA. The AUDIT alcohol consumption questions (AUDIT-C): an effective brief screening test for problem drinking. Ambulatory Care Quality Improvement Project (ACQUIP). Alcohol Use Disorders Identification Test. *Archives of internal medicine* 1998; **158**(16): 1789-95.
22. Bower C, Elliot E. Report to the Australian Government of Health: Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD). 2016.
23. Sparrow S, Chicchettie D, Balla D. Vineland Adaptive Behavior scales, Parent/Caregiver Rating Form. Second ed. Minneapolis, MN: NCS Pearson Inc; 2005.
24. Sparrow S, Cicchetti D, Balla D. Vineland Adaptive Behavior Scales Teacher Rating Form Second Edition. Minneapolis, MN: NCS Pearson Inc; 2006.
25. Ainge D. Life skills checklist for students who identify as Indigenous. *Innovations in Education and Teaching International* 2001; **39**(2): 107-16.
26. Wechsler D. Wechsler Abbreviated Scale of Intelligence Second Edition. Bloomington, MN: Pearson; 2011.
27. Wechsler D, Naglieri JA. Wechsler nonverbal scale of ability. San Antonio, TX: Harcourt Assessment; 2006.
28. Cook JL, Green CR, Lilley CM, et al. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *Can Med Assoc J* 2016; **188**(3): 191-7.
29. Mutch RC, Watkins R, Bower C. Fetal alcohol spectrum disorders: notifications to the Western Australian Register of Developmental Anomalies. *Journal of Paediatrics & Child Health* 2015; **51**(4): 433-6.
30. Bourke J, De Klerk N, Leonard H. Population-Based Prevalence of Intellectual Disability and Autism Spectrum Disorders in Western Australia: A Comparison With Previous Estimates. *Medicine* 2016; **95**: e3737.
31. Astley SJ. Diagnostic Guide for Fetal Alcohol Spectrum Disorders: The 4-Digit Diagnostic Code. Third ed. Seattle: University of Washington; 2004.
32. Mutch RC, Cherian S, Nemba K, et al. Tertiary paediatric refugee health clinic in Western Australia: Analysis of the first 1026 children. *Journal of paediatrics and child health* 2012; **48**(7): 582-7.
33. Chitsabesan P, Lennox C, Theodosiou L, Law H, Bailey S, Shaw J. The development of the comprehensive health assessment tool for young offenders within the secure estate. *Journal of Forensic Psychiatry & Psychology* 2014; **25**(1): 1-25.
34. Cohen E, Mackenzie RG, Yates GL. HEADSS, a psychosocial risk assessment instrument: Implications for designing effective intervention programs for runaway youth. *Journal of Adolescent Health* 1991; **12**(7): 539-44.
35. Delis D, Kaplan E, Kramer J. Delis-Kaplan Executive Function System. The Psychological Corporation, San Antonio, TX: Harcourt Brace & Company; 2001.
36. Adams W, Sheslow D. Wide Range Assessment of Memory and Learning Second Edition. Wilmington, DE: Wide Range; 2004.
37. Wilkinson GD, Robertson GJ. Wide Range Achievement Test Fourth Edition. Lutz, FL: Psychological Assessment Resources; 2006.
38. Semel E, Wiig EH, Secord WA. Clinical Evaluation of Language Fundamentals Fourth Edition, Australian Standardised Edition (CELF-4 Australian). Sydney, NSW: Pearson Clinical and Talent Assessment; 2003.
39. Gould J. Non-standard assessment practices in the evaluation of communication in Australian Aboriginal children. *Clinical linguistics & phonetics* 2008; **22**(8): 643-57.

40. Wagner R, Torgesen J, Rashotte C. Comprehensive Test of Phonological Processing Second Edition (CTOPP-2). Texas, TX: Pro-Ed Incorporated; 2013.
41. Snow PC, Powell MB. What's the story? An exploration of narrative language abilities in male juvenile offenders. *Psychology, Crime & Law* 2005; **11**(3): 239-53.
42. Semel E, Wiig EH, Secord WA. Clinical Evaluation of Language Fundamentals Fourth Edition, Screening Test Australian & New Zealand Language Adapted Edition (CELF-4 Screener). Sydney, NSW: Pearson Clinical and Talent Assessment; 2004.
43. Beery K, Beery N. The Beery-Buktenica Development Test of Visual-Motor Integration: Administration, Scoring and Teaching Manual Sixth Edition. Minneapolis, MN: Pearson; 2010.
44. Henderson AJ, Sugden DA, Barnett AL. Movement Assessment Battery for Children Second Edition (Movement ABC-2). London, UK: The Psychological Corporation; 2007.
45. Mutti MA, Sterling MD, Martin NA, Spalding NV. Quick Neurological Screening Test Manual Third Edition (QNST-3). Novato, CA: Academic Therapy Publications; 2012.
46. Brown C, Dunn W. Adolescent/Adult Sensory Profile User's Manual. Bloomington, MN: Psychological Corp; 2002.
47. Pearce WM, Williams C. The cultural appropriateness and diagnostic usefulness of standardized language assessments for Indigenous Australian children. *International journal of speech-language pathology* 2013; **15**(4): 429-40.

**STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies***

| Section/Topic | Item # | Recommendation | Reported on page # |
|---|---|---|---|
| **Title and abstract** | 1 | (*a*) Indicate the study's design with a commonly used term in the title or the abstract | 1 |
| | | (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found | 2 |
| **Introduction** | | | |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | 4-5 |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | 2;5 |
| **Methods** | | | |
| Study design | 4 | Present key elements of study design early in the paper | 5 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | 6-8 |
| Participants | 6 | (*a*) Give the eligibility criteria, and the sources and methods of selection of participants | 6 |
| Variables | 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | 7-8 |
| Data sources/ measurement | 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | 7-8 |
| Bias | 9 | Describe any efforts to address potential sources of bias | 7 |
| Study size | 10 | Explain how the study size was arrived at | 6 |
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | 8 |
| Statistical methods | 12 | (*a*) Describe all statistical methods, including those used to control for confounding | 8 |
| | | (*b*) Describe any methods used to examine subgroups and interactions | 21-25 |
| | | (*c*) Explain how missing data were addressed | 21-25 |
| | | (*d*) If applicable, describe analytical methods taking account of sampling strategy | |
| | | (*e*) Describe any sensitivity analyses | 11 |
| **Results** | | | |

| | | | |
|---|---|---|---|
| Participants | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | 9 |
| | | (b) Give reasons for non-participation at each stage | 9 |
| | | (c) Consider use of a flow diagram | |
| Descriptive data | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | 9-10; 21-25 |
| | | (b) Indicate number of participants with missing data for each variable of interest | 11; 21-25 |
| Outcome data | 15* | Report numbers of outcome events or summary measures | 10-12;22-25 |
| Main results | 16 | (*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | 2;10-11 |
| | | (*b*) Report category boundaries when continuous variables were categorized | |
| | | (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | |
| Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | 11 |
| **Discussion** | | | |
| Key results | 18 | Summarise key results with reference to study objectives | 12 |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | 12-13 |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | 12-14 |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | 13 |
| **Other information** | | | |
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | 3 |

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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# FETAL ALCOHOL SPECTRUM DISORDER AND YOUTH JUSTICE: A PREVALENCE STUDY AMONG YOUNG PEOPLE SENTENCED TO DETENTION IN WESTERN AUSTRALIA



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# FETAL ALCOHOL SPECTRUM DISORDER AND YOUTH JUSTICE: A PREVALENCE STUDY AMONG YOUNG PEOPLE SENTENCED TO DETENTION IN WESTERN AUSTRALIA

Carol Bower PhD[1,2], Rochelle Watkins PhD[1,2], Raewyn C Mutch FRACP[1,2,3,4], Rhonda Marriott PhD[5], Jacinta Freeman MPH[1], Natalie R Kippin MSP[1,7], Bernadette Safe BSci(OT)[1,3], Carmela Pestell DPsych[1,6], Candy SC Cheung PhD[6], Helen Shield BA (Hons)[6], Lodewicka Tarratt BPsychHons[6], Alex Springall Grad Dip Psych[6], Jasmine Taylor BPsychHons[6], Noni Walker MPH[1], Emma Argiro FRACP[4], Suze Leitão PhD[1,7], Sharynne Hamilton BA(Hons)[1,3], Carmen Condon MPH[1], Hayley M Passmore BA(Hons)[1,3], Roslyn Giglia PhD[1,2]

[1]Telethon Kids Institute, PO Box 855, West Perth, Western Australia 6872

[2]The University of Western Australia, Perth, Western Australia

[3]School of Paediatrics and Child Health, The University of Western Australia, Perth, Western Australia

[4]Child and Adolescent Health Service, Department of Health Western Australia, Perth, Western Australia

[5]School of Psychology and Exercise Science, Murdoch University, Perth, Western Australia

[6]School of Psychology, The University of Western Australia, Perth, Western Australia

[7] School of Psychology and Speech Pathology, Curtin University, Perth, Western Australia

**Corresponding author**:

Professor Carol Bower

Telethon Kids Institute

PO Box 855, WEST PERTH WA 6872, Australia

Telephone: +618 9489 7751

Email: carol.bower@telethonkids.org.au

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**ABSTRACT**

**Objectives:** To estimate the prevalence of Fetal Alcohol Spectrum Disorder (FASD) among young people in youth detention in Australia. Neurodevelopmental impairments due to FASD can predispose young people to engagement with the law. Canadian studies identified FASD in 11 - 23% of young people in corrective services but there are no data for Australia.

**Design:** Multidisciplinary assessment of all young people aged 10 years to 17 years 11 months and sentenced to detention in the only youth detention centre in Western Australia, from May 2015 to December 2016. FASD was diagnosed according to the Australian Guide to the Diagnosis of FASD.

**Participants:** 99 young people completed a full assessment (88% of those consented; 60% of the 166 approached to participate); 93% were male and 74% were Aboriginal.

**Findings:** 88 young people (89%) had at least one domain of severe neurodevelopmental impairment, and 36 were diagnosed with FASD, a prevalence of 36% (95% confidence interval (CI) 27% – 46%).

**Conclusions:** This study, in a representative sample of young people in detention in Western Australia, has documented a high prevalence of FASD and severe neurodevelopmental impairment, the majority of which had not been previously identified. These findings highlight the vulnerability of young people, particularly Aboriginal youth, within the justice system and their significant need for improved diagnosis to identify their strengths and difficulties, and to guide and improve their rehabilitation.

**Strengths and limitations of this study:**

- Study conducted in the only youth detention centre in the Western Australia
- Representative sample of young people in detention in Western Australia
- Comprehensive, multidisciplinary assessment, using Australian diagnostic criteria for FASD
- Inability to obtain information on prenatal alcohol exposure for some young people
- Did not assess the domain of affect regulation and limited formal assessment of domain of adaptive behaviour for some young people

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## INTRODUCTION

Fetal Alcohol Spectrum Disorder (FASD) is characterised by severe, pervasive neurodevelopmental impairment due to prenatal alcohol exposure. Impairment in executive function, memory, language, learning and attention in young people with FASD can result in a range of difficulties including understanding cause and effect, learning from past experiences and decision making.[1-3] These impairments can, in turn, lead and contribute to problems at school and with employment, mental health, social exclusion, substance misuse and early and repeated engagement with the law.[4] In the Fetal Alcohol Follow-up Study of the University of Washington Fetal Alcohol and Drug Unit, of 415 individuals assessed by dysmorphologists to have Fetal Alcohol Syndrome or Fetal Alcohol Effects (median age at follow-up was 14 years of age), 60% had been in trouble with the law and 35% had been incarcerated for a crime.[4]

There are limited data on the prevalence of FASD among young people in correctional systems. A systematic review published in 2011[5] identified three studies, all from Canada[6-8] and a more recent systematic review [9] identified one additional Canadian study.[10] Only one of these studies involved active case ascertainment using clinical assessment to identify FASD using described diagnostic criteria for fetal alcohol syndrome and fetal alcohol effects[11] among 287 youth remanded to a forensic psychiatric assessment unit.[6] One sought mention of FASD (either formally diagnosed or suspected by a physician) in the records of 230 youth attending a sexual offender treatment program [8] and the other two obtained information on FASD by self-report in a survey of youth in custody.[7,10] The identified prevalence of FASD was 10.9%,[8] 11.7%,[7] 21% [10] and 23.3%[6], although the number of cases of undiagnosed FASD in custodial and correctional systems was thought to be high.

There is increasing concern regarding the forensic implications of FASD in Australia[12,13], as the neuropsychological sequelae can affect all aspects of the legal proceedings, including the person

understanding the expectations and providing credible evidence in forensic interviews, fitness to plead, capacity to stand trial and the process of sentencing.[13,14] There are no data on the prevalence of FASD in the justice system in Australia, but it is well-recognised that FASD is under-diagnosed in the general population,[15,16] and a high prevalence of intellectual disability and poor mental health has been identified amongst young people in the justice system. In a study of 65% of young people in eight juvenile justice centres in New South Wales (n=295), 45.8% had borderline or lower intellectual functioning, including 14% with an IQ < 70.[17] Additionally, in a survey of 273 young people serving custodial orders in Victoria, 39% had depressive symptoms, 17% had a positive psychosis screen and 22% had engaged in deliberate self-harm in the past six months.[18] These findings highlight the possibility of undiagnosed FASD amongst these young people.

Based on currently available data, FASD is diagnosed more commonly and at higher rates in Aboriginal compared with non-Aboriginal children in Australia.[19-21] Of concern, Aboriginal young people are over 20 times more likely to be in detention compared with non-Aboriginal young people in Australia[22] and, in Western Australia between 2015 and 2016, 73% of youth in detention were Aboriginal.[23] Given the forensic implications of FASD and neurodevelopmental impairments, and in the absence of information on FASD in the Australian justice system, we undertook this study to assess the prevalence of FASD among young people in youth detention in Western Australia.

## METHODS

A paper describing the full study protocol has been published[24] and is summarised here.

### Setting

We conducted the study between May 2015 and December 2016, in the Banksia Hill Detention Centre (BHDC), the only youth detention centre in Western Australia. Males and females (94% male), aged 10 to 18 years, reside at the Centre either on remand or sentenced to detention, 73% are Aboriginal and, in 2015-6, the average daily occupancy was 133 young people.[23] Sentenced youth

spend approximately 130 days in detention. The main offences committed by youth offenders in Western Australia are theft, unlawful entry with intent and acts intended to cause injury.[25]

**Ethics and Governance**

Ethics approval was given by the Western Australian Aboriginal Health Ethics Committee (approval number 582) and the University of Western Australia Human Research Ethics Committee (approval number RA/4/1/7116). The former Department of Corrective Services granted research approval (DCS; project ID 335). The former Department for Child Protection and Family Support (DCPFS) also gave approval for the research to include young people in their care (approval number 2015/8981).

A Consumer and Community Reference Group, a Steering Group, and a Reference Group of DCS and DCPFS representatives, provided advice and guidance to the research team.

**Participants**

All young people sentenced to detention within BHDC, aged 10-17 years 11 months were eligible to participate. To allow sufficient time for completion of the assessment, only those young people with at least two further weeks of detention from the time they were invited to participate were included.

**Recruitment**

Participants were recruited by a face to face approach from the project research officer, who identified eligible young people from the Centre census each week, up to a maximum of four per week (the capacity of the assessment team, given assessments were restricted to only two days per week). If a young person expressed interest in being involved in the study, the research officer explained the purpose of the study using simple language and pictorial information sheets and assent forms. When a young person gave assent, written consent was then sought from their

identified responsible adult or, in the case of young people in the care of DCPFS, consent was sought directly from the DCPFS case manager responsible for that young person.

**Data collection**

The research officer used standardised forms to collect and record information from the participant (psychosocial checklist), the responsible adult or the child protection case managers (background history, prenatal alcohol exposure, adaptive behaviour, executive functioning), detention centre teachers (adaptive behaviour, executive functioning) and youth custodial officers (adaptive behaviour, social skills, social communication).

The Alcohol Use Disorders Identification Test – Consumption (AUDIT-C)[26] questions were used to assess prenatal alcohol exposure if the young person's birth mother was their responsible adult. When this was not possible, other evidence of exposure was sought from the responsible adult, such as observation of alcohol use during pregnancy. Prenatal alcohol exposure was categorised according to the Australian Guide to the Diagnosis of FASD[27] as: (i) no exposure, if there was confirmed absence of prenatal alcohol; (ii) confirmed exposure, if the AUDIT-C score was 1-4, or there was confirmed use but the level of exposure was not known; (iii) confirmed high risk exposure, if the AUDIT-C score was 5+ or it was reliably known that exposure was at a high level (such as consumption of 5 or more standard drinks on at least one occasion in pregnancy); or (iv) unknown exposure, if there was no or inconsistent information on whether there was prenatal alcohol exposure.

**Diagnostic Criteria**

We used the criteria contained in the Australian Guide to the Diagnosis of FASD (Table 1).[27] These criteria were confirmed only after the study protocol was designed and, as Affect Regulation was added as a domain of neurodevelopmental impairment in the new criteria, this domain was not formally assessed in this study.

We intended to assess the adaptive functioning/social skills/social communication domain using the Vineland Adaptive Behaviour Scales – parent/caregiver rated and teacher rated forms,[28,29] the Life Skills Checklist and an informal social skills and communication questionnaire.[30] However, this was not possible for 81 young people. Reasons included informants not knowing the participants for long enough, and non-return of or incomplete forms.

**Clinical assessments**

A multidisciplinary team (paediatrician, occupational therapist, speech pathologist, provisional neuropsychologists with supervision) conducted the clinical assessment, blind to information on prenatal alcohol exposure. For participants who spoke English as an additional language, language assessment was conducted informally by the speech pathologist working in collaboration with accredited interpreters. Table 2 lists the assessment tools used by the clinicians. On completion of the assessment, the multidisciplinary team met to review the findings and carefully consider the results of all the assessments, together with identified co-morbidities (such as attention-deficit/hyperactivity disorder, intellectual disability) and history (such as cultural background, lived trauma, disrupted attachment, schooling history) for each participant. If there was confirmed prenatal alcohol exposure and the young person had three or more domains severely impaired (>=2SD), and there were no other causes identified that would account for the impairments, then a diagnosis of FASD was ascribed. A diagnosis of FASD was always made conservatively and only assigned when diagnostic criteria were fulfilled and other causes were considered not to account for the measured difficulties.

The team prepared a report for every participant, which detailed the results of the assessments and recommendations for supporting and working with the young person, using the young person's identified strengths. This report not only served to establish a baseline to monitor progress, but also provided guidance regarding health and medical needs, the development of appropriate educational or occupational goals, factors to consider for interventions, compensatory strategies and overall

case management. When possible, members of the research team discussed the report with the young person using simple verbal feedback combined with simple visual aids as needed. The young person received a paper copy of the report upon release from detention. The reports were also provided to the young person's responsible adult and, with consent, to staff in youth justice services (including health and psychological services), lawyers and other agencies as indicated.

**Pilot study**

We conducted a pilot study in May 2015 with 11 young people. As only minor modifications were made to the processes for enrolment and assessment based on the pilot study, these 11 cases were included in the full study, which ran until December 2016.

**Statistical methods**

Descriptive analyses were conducted using IBM SPSS Statistics for Windows, Version 24, Armonk, NY, USA, released 2016.

**RESULTS**

**Participation**

Between May 2015 and December 2016, 213 young people were identified as eligible for inclusion, however, 47 were not approached due to our inability to undertake more than four assessments per week. Of those approached, 154 young people assented to participate (93%) and 12 young people declined. Of the 154 assenting young people, the responsible adult for 113 of them gave written consent for their participation (73%). Consent was declined for 3 young people, 10 responsible adults gave verbal but not written consent (written consent was a requirement of the study), 14 young people either turned 18 or were released before written consent was obtained, and we were

unable to contact the responsible adult for the remaining 14 young people, despite repeated attempts. Following assent and consent, five young people were released before assessment. The remaining 108 underwent assessment (96% of those consented); 99 of whom completed a full assessment (88% of those consented; 60% of the 166 approached to participate).

**Characteristics of participants**

The majority of young people with a completed assessment were male (92; 93%) and Aboriginal (73; 74%), and a third were aged 17 years (Table 3). The responsible adult for most young people assessed was a parent (62; 63%), 24 (24%) had another person as their guardian (frequently a grandmother), and 13 (13%) were in the care of the DCPFS. Half the young people lived in the metropolitan area. There were no significant differences between these proportions and those for young people assented but not consented (Table 3).

**Diagnosis of FASD**

A total of 36 young people were diagnosed with FASD, a prevalence of 36% (95% confidence interval (CI) 27% – 46%). All diagnoses were in the category of FASD with < 3 sentinel facial features; two were non-Aboriginal (FASD prevalence=8%; CI 1%-25%), 34 were Aboriginal (FASD prevalence=47%; CI 35%-58%). Two young people had a FASD diagnosis prior to entering the study. One was diagnosed 5-6 years previously and one was a more recent diagnosis but had not had all domains assessed at that time. Both young people had the diagnosis of FASD confirmed using the new Australian criteria.[27]

**Prenatal alcohol exposure (Table 4)**

Prenatal alcohol exposure amongst fully assessed young people was confirmed for 47 (47%), 28 (28%) of whom had documented high level exposure. Prenatal exposure was unknown for 13 young people (13%) and 39 were confirmed as not exposed to prenatal alcohol (39%).

**Neurodevelopmental domains with severe impairment**

Eleven of the fully assessed young people had no domains of severe neurodevelopmental impairment (11%), 23 had one or two domains severely impaired and the remaining 65 had three or more domains severely impaired (Table 5). Just over half the young people diagnosed with FASD had three or four domains severely impaired, the remainder had five or more severely impaired domains. The individual domains that were severely impaired are shown in Table 6. The majority of young people with FASD had severe impairment in the academic (86%), attention (72%), executive functioning (78%) and/or language (69%) domains. Severe impairment in memory (56%), motor skills (50%) and cognition (36%) were also commonly found in the young people with FASD. Severe impairment in these domains was also seen amongst the young people without a FASD diagnosis, but at lower levels. Only one young person (who did not have FASD) was identified with a severe impairment in the brain structure/neurology domain. Overall, 25 young people (25%) were assessed to have an IQ score below 70, using the WASI-II or WNV;[31,32] ten without FASD (16%) and 15 with FASD (42%).

Of the 13 young people with unknown prenatal alcohol exposure, there were nine with three or more severely impaired domains. If they had been exposed to alcohol prenatally, then a diagnosis of FASD may have been indicated. Additionally, among eight young people with known exposure to prenatal alcohol who did not have a FASD diagnosis but whose adaptive functioning/social skills/social communication domain had not been assessed, four had two domains meeting severe

impairment. Hence, for these four young people, if they had had severe impairment in adaptive functioning, a diagnosis of FASD is also possible.

**Sentinel facial features**

The majority of young people (73; 74%) had no characteristic facial features of FASD and none had all three facial features (Table 6). One young person (without FASD) had a palpebral fissure length ≤ 2 standard deviations, 19 had a lip philtrum rank 4 or 5 (13 of whom had FASD), and 18 had an upper lip rank 4 or 5 (8 with FASD).

**DISCUSSION**

This is the first study to estimate the prevalence of FASD in youth detention in Australia. We found that 36% of 99 young people aged 13-17 years were diagnosed with FASD. Study diagnoses were made according to the Australian diagnostic criteria[27] - all cases received a diagnosis of FASD with less than 3 sentinel facial features. This is the highest reported prevalence of FASD in a youth justice setting world-wide. There are four other studies, all from Canada,[6-8,10] with FASD prevalence ranging from 10.9% to 23.3%, all outside the lower 95% confidence interval of this study's estimate. Only one of these studies clinically assessed young people to make the diagnosis[6] using diagnostic criteria[11] that differ from the Australian Guide,[27] while the others used self-report or record review to identify cases and differing criteria for inclusion as a FASD. Hence they may underestimate the true prevalence, although two of these studies were in special groups (sexual offenders,[8] young people in a psychiatric unit[6]) in which FASD may be more common.

However, for several reasons, our prevalence of 36% may also be an underestimate. First, we did not formally assess the domain of affect regulation, and self-reported mental health problems are

common among youth in custody in Australia.[17,18] The affect regulation domain was included for the first time in the new Canadian guidelines for FASD diagnosis[3] and the Australian Diagnostic Guide,[27] both of which were published after our study had started. Second, we estimate that a possible further four cases of FASD may have been identified had we been able to formally assess the adaptive functioning/social skills/social communication domain and found it impaired in young people with prenatal alcohol exposure and two other impaired domains. This was not possible because we were unable to obtain formal measures of adaptive functioning for the majority of young people although, informally, the fact of being in detention suggests impaired adaptive functioning. Third, we were not able to determine whether there had been prenatal alcohol exposure for 13 young people and, of these, nine had three or more domains of impairment, so they may also have met the diagnostic criteria had they been exposed to alcohol prenatally. Fourth, the brain structure/neurology domain was only assessed clinically - no neuro-imaging was undertaken, so impairment in this domain may also be underestimated.

Given the known high risk of young people with FASD engaging with the law[4] it is not surprising that, in this study, the overall prevalence of FASD is greater than population estimates. The prevalence in Aboriginal youth was 47%, more than twice that of the highest population estimate of FASD in Australia of 19%, reported in a remote, mainly Aboriginal, population of 7-8 year olds.[21] In the Canadian studies, FASD prevalence in Aboriginal youth ranged from 19% to 36%.[7,8,10] Corresponding prevalence in non-Aboriginal Canadian youth ranged from 4-6%, similar to our study of 8%, also much higher than general population estimates in Western Australia (0.03 per 1000 non-Aboriginal)[33] and the worldwide estimate of 7.7 per 1000. [34] Furthermore, the prevalence of severe neurodevelopmental impairment in our study is almost three times as high as the 31% found in the study of Fitzpatrick et al.[21]

The greater prevalence of FASD in Aboriginal populations corresponds with higher rates of high level alcohol consumption in these populations,[35] but this observation fails to acknowledge the complex reasons for higher alcohol use. Past colonial policies such as the removal of Aboriginal children from their families and resultant dispossession from land, community and culture, as well as the historical role of the criminal justice system and Aboriginal incarceration are well documented.[36,37] In addition, these policies have left a legacy: high levels of family violence, drug and alcohol misuse, mental health problems, poverty, disadvantage, marginalisation, trauma and incarceration have been well documented as traversing generations of Aboriginal families.[36-39] High population rates of FASD in Aboriginal young people are likely to be directly responsible, in part, for the high rate of Aboriginal youth incarceration.

Our study has several strengths. It was conducted in the only youth detention facility in Western Australia, and there was a high level of engagement in the study – 93% of the young people approached gave assent and 73% of their responsible adults gave written consent for participation. The age, sex and ethnic profile of the sample was similar to all young people in BHDC at the time of the study.[23] Thus the sample is likely to be representative of all young people in detention in WA.

A further positive feature of the study was the assessment, by a multidisciplinary team, of nine neurodevelopmental domains and the development of a report specific to each young person. The report included recommendations for working with the young person based on their strengths and areas of difficulty, and feedback was given to the young people, their responsible adults, detention centre and other youth justice staff and staff from other relevant agencies, to help guide their management while in detention and upon release. Importantly, impairment in domains such as language, executive function, memory and cognition, may contribute to offending behaviours and/or difficulties in negotiating all aspects of the justice system. [40]

This assessment also identified a high level of severe neurodevelopmental impairment in participants, with only 11% of young people without at least one domain of severe

neurodevelopmental impairment, regardless of a diagnosis of FASD. Twenty-five young people (25%) were assessed to have an IQ score < 70, higher than the 14% found in the study of young people in custody in New South Wales [17] and much higher than in the general population in Western Australia (1.7% overall; 3.9% in Aboriginal children).[41] Only two young people had been diagnosed with FASD prior to participation in this study, similar to the study of Fast et al,[6] where only three of 67 cases of FASD had been previously diagnosed. For many of these young people, this was the first time they had received a comprehensive assessment to examine their strengths and difficulties, despite attending school and, in many cases, prior engagement with child protection services and the justice system. These are missed opportunities for earlier diagnosis and intervention, which may have prevented or mitigated their involvement with justice services.

Youth Justice Services in Western Australia are responsible for the safety, security and rehabilitation of young people in custody and young people engaged with these services in the community.[23] The high burden of FASD and significant neurodevelopmental impairment we found among youth sentenced to detention highlights the need for policy and practice responses to efficiently identify these individuals in detention and the wider justice system; to provide appropriate rehabilitation and therapeutic interventions during detention and following release; and to ensure the justice workforce is suitably skilled to work with individuals with significant neurodevelopmental impairment. Already, government agencies are working with members of our research team to explore how routine assessment of neurodevelopmental impairments among young people can be established within the detention centre and are also working with researchers implementing training resources to upskill staff in how best to manage and provide care for young people with neurodevelopmental impairments.

More broadly and of prime importance, policy and practice responses also need to prioritise health promotion to reduce alcohol use in pregnancy and hence address primary prevention of FASD.

**Conclusions**

This study, in a representative sample of young people in detention in Western Australia, has documented a high prevalence of FASD and severe neurodevelopmental impairment, the majority of which had not been previously identified. These findings highlight the vulnerability of young people within the justice system and their significant need for improved diagnosis to identify their strengths and difficulties, and to guide and improve their rehabilitation.

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**Declaration of interests**

The authors declare no conflicts of interest.

**Role of the funding sources**

The funders had no role in the study design, data collection, analysis, interpretation of the data, writing the paper or in the decision to submit the paper for publication. The authors have not been

paid to write this article by a pharmaceutical company or other agency. The corresponding author (Carol Bower) had full access to all the data in the study and had final responsibility for the decision to submit for publication.

**Data Sharing Statement**

The broader study is ongoing and we will not be making our data available at this time.

**Contribution of the authors**

Carol Bower: literature search, study design, collaboration with stakeholders, data analysis, data interpretation, writing first draft

Rochelle Watkins: literature search, study design, collaboration with stakeholders, data interpretation, writing

Raewyn Mutch: study design, collaboration with stakeholders, clinical assessments, data collection, data interpretation, writing

Rhonda Marriott: collaboration with stakeholders, cultural guidance

Jacinta Freeman: study design, collaboration with stakeholders, project management, data interpretation

Natalie Kippin: study design, collaboration with stakeholders, clinical assessments, data collection, data interpretation, writing

Bernadette Safe: study design, collaboration with stakeholders, clinical assessments, data collection, data interpretation, writing

Carmela Pestell: study design, supervision of provisional neuropsychologists, data interpretation, writing

Candy SC Cheung: study design, clinical assessments, data collection, data interpretation

Helen Shield: clinical assessments, data collection, data checking, data interpretation

Lodewicka Tarratt: clinical assessments, data collection, data interpretation

Alex Springall: clinical assessments, collaboration with stakeholders, data collection, data interpretation

Jasmine Taylor: clinical assessments, data collection, data interpretation

Noni Walker: collaboration with stakeholders, project management, data interpretation

Emma Agiro: clinical assessments, data collection, data checking, data interpretation

Suze Leitão: professional support to speech pathologist, collaboration with stakeholders, data interpretation, writing

Sharynne Hamilton: collaboration with stakeholders, cultural guidance, writing

Carmen Condon: data management, data checking, data analysis, data interpretation

Hayley Passmore: collaboration with stakeholders, data interpretation, writing

Roslyn Giglia: study design, collaboration with stakeholders, project management, data interpretation

All authors read and had the opportunity to contribute to drafts of the paper. All authors approve the final paper.

**Table 1. Australian diagnostic criteria and categories for Fetal Alcohol Spectrum Disorder[27]**

| Diagnostic criteria | Diagnostic categories | |
|---|---|---|
| | FASD with 3 Sentinel Facial Features^ | FASD with < 3 Sentinel Facial Features |
| Prenatal alcohol exposure | Confirmed or unknown | Confirmed |
| Neurodevelopmental domains<br>- Brain structure/Neurology<br>- Motor Skills<br>- Cognition<br>- Language<br>- Academic Achievement<br>- Memory<br>- Attention<br>- Executive Function, including impulse control and hyperactivity<br>- Affect Regulation<br>- Adaptive Behaviour, Social Skills or Social Communication | Severe impairment* in at least 3 neurodevelopmental domains | Severe impairment* in at least 3 neurodevelopmental domains |
| Sentinel facial features<br>- Short palpebral fissure<br>- Smooth philtrum<br>- Thin upper lip | Presence of 3 sentinel facial features | Presence of 0, 1 or 2 sentinel facial features |

* Severe impairment is defined as either a global score or a major subdomain score on a standardised validated neurodevelopmental scale that is ≤2 SD below the mean or < 3rd percentile.
^FASD with 3 Sentinel Facial Features similar to Fetal Alcohol Syndrome

**Table 2. Diagnostic assessments used by multidisciplinary diagnostic team for each domain assessed.**

| | |
|---|---|
| **Brain structure/Neurology** | Comprehensive medical history, and psychosocial and clinical examination including health, wellbeing, substance use and at-risk behaviours, mood, vision, hearing, motor, and sensation. |
| **Motor Skills** | Movement Assessment Battery for Children 2nd edition, age band 3[42]<br>Beery Buktenica Developmental Test of Visual Motor Integration 6th edition, including subtests Visual Perception and Motor Coordination[43]<br>Quick Neurological Screening Test 3rd edition[44]<br>Handwriting screen (informal)*<br>Motor speech diadochokinetic rate*<br>Observation of articulation* |
| **Cognition** | Wechsler Abbreviated Scale of Intelligence 2nd Edition[31]<br>Wechsler Non-Verbal Test of Intelligence[32] |
| **Language** | Clinical Evaluation of Language Fundamentals, 4th Edition, Australian[45]<br>Non-word repetition task (informal)<br>Self and/or caregiver report (informal)<br>Oral narrative (informal)*<br>Receptive and expressive language tasks (informal)* |
| **Academic Achievement** | Comprehensive Test of Phonological Processing 2nd Edition, Elision subtest[46]<br>Wide Range Achievement Test, Fourth Edition[47]– Reading Comprehension, Word Reading, Sentence Comprehension, Math Computation, Spelling<br>Written narrative (informal)* |
| **Memory** | Wide Range Assessment of Memory & Learning 2nd Edition, Screening Memory Index [48] |
| **Attention** | Delis-Kaplan Executive Function System[49] - Colour-Word Interference (Colour Naming & Word Reading), Trail Making (Visual Scanning, Number/Letter Switching + errors)<br>Wechsler Non-Verbal Test of Intelligence[32] Spatial Span Forwards<br>Sensory Profile Adolescent/Adult self-questionnaire [50]* |
| **Executive Function (including impulse control and hyperactivity)** | Delis-Kaplan Executive Function System[49]-Colour-Word Interference (Inhibition, Inhibition/Switching + errors), Trail Making (Number Sequencing & Letter Sequencing) and Category fluency<br>Wechsler Non-Verbal Test of Intelligence[32] Spatial Span Backwards subtest<br>WASI-II [31] -Similarities & Matrix Reasoning subtests<br>Behaviour Rating Inventory of Executive Functioning[51] |
| **Adaptive Behaviour, Social Skills/Communication** | Vineland Adaptive Behaviour Scales (Parent/Caregiver and Teacher versions), 2nd Edition[28]<br>Social communication checklist (informal)* |

* Supplementary information to the primary diagnostic measure/s

**Table 3. Demographic characteristics of young people who completed the full FASD assessment compared with those assenting but written consent not obtained.**

| | Completed assessment (N=99) N (%) | Assented but not consented (N=41) N (%) | Statistical test result |
|---|---|---|---|
| **Gender*** | | | |
| Male | 92 (93) | 40 (98) | Fisher's Exact P=0.7 |
| Female | 6 (6) | 1 (2) | |
| **Age in years** | | | $\chi^2$ = 0.5; P= 0.97 |
| 17 | 33 (33) | 15 (37) | |
| 16 | 23 (23) | 10 (24) | |
| 15 | 23 (23) | 9 (22) | |
| 14 | 16 (16) | 5 (12) | |
| 13 | 4 (4) | 2 (5) | |
| **Ethnicity** | | | |
| Australian non-Aboriginal | 16 (16) | 9 (22) | $\chi^2$ = 1.5; P= 0.5 |
| Australian Aboriginal | 73 (74) | 30 (73) | |
| Other** | 10 (10) | 2 (5) | |
| **Place of residence** | | | |
| Metropolitan | 50 (51) | 22 (54) | $\chi^2$ = 0.1; P= 0.7 |
| Rural/Regional/Remote | 49 (49) | 19 (46) | |
| **Legal guardian** | | | |
| Parent | 62 (63) | 24 (58) | $\chi^2$ = 3.5; P= 0.2 |
| Guardian | 24 (24) | 15 (37) | |
| Child protection^ | 13 (13) | 2 (5) | |

* includes those who identify as transgender; ** includes young people of New Zealand, Asian, African ethnicity; ^ Child Protection and Family Support Services

**Table 4. Prenatal alcohol exposure for all young people completing the full FASD assessment**

| **Prenatal alcohol exposure** | **Total completing FASD assessment (N=99) N (%)** | **Diagnosed with FASD (N=36) N (%)** | **Not diagnosed with FASD (N=63) N (%)** |
|---|---|---|---|
| Confirmed | 47 (47) | 36 (100) | 11 (17) |
| *Confirmed high risk* | *28 (28)* | *22 (61)* | *6 (10)* |
| No exposure | 39 (39) | 0 | 39 (62) |
| Exposure unknown | 13 (13) | 0 | 13 (21) |

**Table 5. Total number of severely impaired neurodevelopmental domains amongst all young people completing the full FASD assessment.**

| Number of domains severely impaired | Total completing FASD assessment (N=99) N (%) | Diagnosed with FASD (N=36) N (%) | Not diagnosed with FASD (N=63) N (%) |
|---|---|---|---|
| 0 | 11 (11) | 0 | 11 (17) |
| 1 | 13 (13) | 0 | 13 (21) |
| 2 | 10 (10) | 0 | 10 (16) |
| 3 | 26 (26) | 9 (25) | 17 (27) |
| 4 | 16 (16) | 12 (33) | 4 (6) |
| 5 | 11 (11) | 5 (14) | 6 (10) |
| 6 | 6 (6) | 5 (14) | 1 (2) |
| 7 | 6 (6) | 5 (14) | 1 (2) |
| 8 | 0 | 0 | 0 |
| 9 | 0 | 0 | 0 |

The domains assessed were: brain structure/neurology; motor skills; cognition; language; academic achievement; memory; attention; executive function; adaptive behaviour, social skills or social communication.

**Table 6. Diagnostic features of young people completing full FASD assessment**

| | Total completing FASD assessment (N=99) N (%) | Diagnosed with FASD N=36 N (%) | Not diagnosed with FASD N=63 N (%) |
|---|---|---|---|
| **Neurodevelopmental domains impaired*** | | | |
| Academic achievement | 61 (62) | 31 (86) | 30 (48) |
| Attention | 54 (55) | 26 (72) | 28 (44) |
| Executive function | 53 (54) | 28 (78) | 25 (40) |
| Language | 45 (45) | 25 (69) | 20 (32) |
| Memory | 38 (38) | 20 (56) | 18 (29) |
| Motor skills | 29 (29) | 18 (50) | 11 (17) |
| Cognition | 21 (21) | 13 (36) | 8 (13) |
| Adaptive functioning/social skills/social communication** | 6 (6) | 4 (11) | 2 (3) |
| Brain structure/neurology | 1 (1) | 0 | 1 (2) |
| **Number of sentinel facial features** | | | |
| 0 | | 21 (58) | 52 (83) |
| 1 | | 9 (25) | 5 (8) |
| 2 | | 6 (17) | 6 (9) |
| 3 | | 0 | 0 |

* Domains according to the Australian Guide to the Diagnosis of FASD, excluding Affect Regulation[27]

** 29 young people with FASD and 52 without FASD did not have this domain assessed.

**REFERENCES**

1. Stratton K, Howe C, Battaglia F. Fetal Alcohol Syndrome: Diagnosis, epidemiology, prevention, and treatment. Institute of Medicine. Washington, DC: National Academy Press; 1996.
2. Connor PD, Sampson PD, Bookstein FL, Barr HM, Streissguth AP. Direct and indirect effects of prenatal alcohol damage on executive function. *Developmental neuropsychology* 2000; **18**(3): 331-54.
3. Cook JL, Green CR, Lilley CM, et al. Fetal alcohol spectrum disorder: a guideline for diagnosis across the lifespan. *Can Med Assoc J* 2016; **188**(3): 191-7.
4. Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K, Young JK. Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics* 2004; **25**(4): 228-38.
5. Popova S, Lange S, Bekmuradov D, Mihic A, Rehm J. Fetal alcohol spectrum disorder prevalence estimates in correctional systems: A systematic literature review. *Canadian Journal of Public Health* 2011; **102**(5): 336-40.
6. Fast DK, Conry J, Loock C. Identifying fetal alcohol syndrome among youth in the criminal justice system. *Journal of Developmental & Behavioral Pediatrics* 1999; **20**(5): 370-2.
7. Murphy A, Chittenden M. Time Out II: A Profile of BC Youth in Custody. Vancouver, 2005.
8. Rojas E, Gretton HM. Background, offence characteristics, and criminal outcomes of Aboriginal youth who sexually offend: a closer look at Aboriginal youth intervention needs. *Sex Abuse* 2007; **19**: 257-83.
9. Hughes N, Clasby B, Chitsabesan P, Williams H. A systematic review of th prevalence of foetal alcohol syndrome disorders among young people in the criminal justice system. *Cogent Psychology* 2016; **3**: 1-8.
10. Smith A, Cox K, Poon C, Stewart D. Time out III:A profile of BC youth in custody. Vancouver, 2013.
11. Sokol RJ, Clarren SK. Guidelines for use of terminologydescribing the impact of prenatal alcoholon the offspring. *Alcoholism, clinical and experimental research* 1989; **13**: 597-8.
12. Douglas H, Hammill J, Hall W, Russell EA. Judicial views of foetal alcohol spectrum disorder in Queensland's criminal justice system. *Journal of Judicial Administration* 2012; **21**(3): 178-88.
13. Freckleton I. Sentencing offenders with foetal alcohol spectrum disorder (FASD): the challenge of effective managment. *Psychiatry, Psychology and Law* 2016; **23**(6).
14. Children's Court of Western Australia. The state of Western Australia -v-BB. Perth; 2015.
15. Payne J, France K, Henley N, et al. Changes in health professionals' knowledge, attitudes and practice following provision of educational resources about prevention of prenatal alcohol exposure and fetal alcohol spectrum disorder. *Paediatric and perinatal epidemiology* 2011; **25**(4): 316-27.
16. Elliott EJ, Payne J, Morris A, Haan E, Bower C. Fetal alcohol syndrome: a prospective national surveillance study. *Archives of disease in childhood* 2008; **93**(9): 732-7.
17. Haysom L, Indig D, Moore E, Gaskin C. Intellectual disablity in young peope in custody in New South Wales, Australia - prevalence and markers. *Journal of Intellectual Disability Research* 2914; **doi:101111/jir.12109**.
18. Kinner SA, Degenhardt L, Coffey C, Sawyer S, Hearps S, Patton G. Complex health needs in the youth justice system: a survey of community-based and custodial offenders. *Journal of Adolescent Health* 2014; **54**: 521-6.
19. Mutch RC, Watkins R, Bower C. Fetal alcohol spectrum disorders: Notifications to the Western Australian Register of Developmental Anomalies. *Journal of paediatrics and child health* 2014; **51**(4): 433-6.
20. Fitzpatrick JP, Latimer J, Carter M, et al. Prevalence of fetal alcohol syndrome in a population-based sample of children living in remote Australia: the Lililwan Project. *Journal of paediatrics and child health* 2015; **51**(4): 450-7.

21. Fitzpatrick JP. Neurodevelopmental outcomes and fetal alcohol spectrum disorders (FASD) in remote Australian Aboriginal children: The Lililwan Project. Sydney, NSW: University of Sydney; 2015.
22. Australian Institute of Health and Welfare. Youth detention population in Australia 2016. Canberra: Australian Government, 2016.
23. Department of Corrective Services. 2015-2016 Annual Report, Department of Corrective Services, Government of Western Australia. 2016. http://www.correctiveservices.wa.gov.au/about-us/statistics-publications/dcs-annual-report.aspx (accessed 23 Nov 2017.
24. Passmore HM, Giglia R, Watkins RE, et al. Study protocol for screening and diagnosis of fetal alcohol spectrum disorders (FASD) among young people sentenced to detention in Western Australia. *BMJ Open* 2016; **6**(6): e012184.
25. Australian Bureau of Statistics. http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4519.0~2015-16~Main%20Features~Youth%20offenders~4.(Accessed 23 Nov 2017
26. Bush K, Kivlahan DR, McDonell MB, Fihn SD, Bradley KA. The AUDIT Alcohol Consumption Questions (AUDIT-C): An effective brief screening test for problem drinking. *Archives of internal medicine* 1998; **158**(16): 1789-95.
27. Bower C, Elliott EJ, Zimmet M, et al. Australian guide to the diagnosis of foetal alcohol spectrum disorder: a summary. *Journal of paediatrics and child health* 2017; **53**: 1021-3.
28. Sparrow S, Chicchettie D, Balla D. Vineland Adaptive Behavior scales, Parent/Caregiver Rating Form. Second ed. Minneapolis, MN: NCS Pearson Inc; 2005.
29. Sparrow S, Cicchetti D, Balla D. Vineland Adaptive Behavior Scales Teacher Rating Form Second Edition. Minneapolis, MN: NCS Pearson Inc; 2006.
30. Ainge D. Life skills checklist for students who identify as Indigenous. *Innovations in Education and Teaching International* 2001; **39**(2): 107-16.
31. Wechsler D. Wechsler Abbreviated Scale of Intelligence Second Edition. Bloomington, MN: Pearson; 2011.
32. Wechsler D, Naglieri JA. Wechsler nonverbal scale of ability. San Antonio, TX: Harcourt Assessment; 2006.
33. Mutch RC, Watkins R, Bower C. Fetal alcohol spectrum disorders: notifications to the Western Australian Register of Developmental Anomalies. *Journal of Paediatrics & Child Health* 2015; **51**(4): 433-6.
34. Lange S, Probst C, Gmel G, Rehm J, Burd L, Popova S. Global Prevalence of Fetal Alcohol Spectrum Disorder Among Children and Youth: A Systematic Review and Meta-analysis. *Jama, Pediatr* 2017; **171**: 948-56.
35. Fitzpatrick JP, Latimer J, Ferreira ML, et al. Prevalence and patterns of alcohol use in pregnancy in remote Western Australian communities: The Lililwan Project. *Drug and Alcohol Review* 2015; **34**(3): 329-39.
36. Atkinson J. Trauma trails, recreating song lines: the transgenerational effects of trauma in Indigenous Australia. North Melbourne: Spionifex Press; 2002.
37. Human Rights and Equal Opportunity Commission. Bringing them home: report of the national inquiry into the separation of Aboriginal and Torres Strait Islander children from their families. Sydney: Human Rights and Equal Opportunity Commission, 1997.
38. Chappell C, Heiner R. The intergenerational transmission of family aggression. *Journal of Famiily Violence* 1990; **5**(2): 135-9.
39. Daly AE, Smith DE. Reproducing exclusion or inclusion? Implications for the wellbeing of Indigenous Australian children: Australian National University, 2003.
40. Douglas H. The sentencing response to defendants with foetal alcohol spectrum disorder. *Crim L J* 2010; **34**: 221-39.

41. Bourke J, De Klerk N, Leonard H. Population-Based Prevalence of Intellectual Disability and Autism Spectrum Disorders in Western Australia: A Comparison With Previous Estimates. *Medicine* 2016; **95**: e3737.
42. Henderson AJ, Sugden DA, Barnett AL. Movement Assessment Battery for Children Second Edition (Movement ABC-2). London, UK: The Psychological Corporation; 2007.
43. Beery K, Beery N. The Beery-Buktenica Development Test of Visual-Motor Integration: Administration, Scoring and Teaching Manual Sixth Edition. Minneapolis, MN: Pearson; 2010.
44. Mutti MA, Sterling MD, Martin NA, Spalding NV. Quick Neurological Screening Test Manual Third Edition (QNST-3). Novato, CA: Academic Therapy Publications; 2012.
45. Semel E, Wiig EH, Secord WA. Clinical Evaluation of Language Fundamentals Fourth Edition, Australian Standardised Edition (CELF-4 Australian). Sydney, NSW: Pearson Clinical and Talent Assessment; 2003.
46. Wagner R, Torgesen J, Rashotte C. Comprehensive Test of Phonological Processing Second Edition (CTOPP-2). Texas, TX: Pro-Ed Incorporated; 2013.
47. Wilkinson GD, Robertson GJ. Wide Range Achievement Test Fourth Edition. Lutz, FL: Psychological Assessment Resources; 2006.
48. Adams W, Sheslow D. Wide Range Assessment of Memory and Learning Second Edition. Wilmington, DE: Wide Range; 2004.
49. Delis D, Kaplan E, Kramer J. Delis-Kaplan Executive Function System. The Psychological Corporation, San Antonio, TX: Harcourt Brace & Company; 2001.
50. Brown C, Dunn W. Adolescent/Adult Sensory Profile User's Manual. Bloomington, MN: Psychological Corp; 2002.
51. Gioia GA, Isquith P, Guy SC, Kenworthy L. Behavior Rating Inventory of Executive Function (BRIEF): Lutz, FL: Psychological Assessment Resource; 2000.

**STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies***

| Section/Topic | Item # | Recommendation | Reported on page # |
|---|---|---|---|
| **Title and abstract** | 1 | (*a*) Indicate the study's design with a commonly used term in the title or the abstract | 1 |
| | | (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found | 2 |
| **Introduction** | | | |
| Background/rationale | 2 | Explain the scientific background and rationale for the investigation being reported | 4-5 |
| Objectives | 3 | State specific objectives, including any prespecified hypotheses | 2;5 |
| **Methods** | | | |
| Study design | 4 | Present key elements of study design early in the paper | 5 |
| Setting | 5 | Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection | 6-8 |
| Participants | 6 | (*a*) Give the eligibility criteria, and the sources and methods of selection of participants | 6 |
| Variables | 7 | Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable | 7-8 |
| Data sources/ measurement | 8* | For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group | 7-8 |
| Bias | 9 | Describe any efforts to address potential sources of bias | 7 |
| Study size | 10 | Explain how the study size was arrived at | 6 |
| Quantitative variables | 11 | Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why | 8 |
| Statistical methods | 12 | (*a*) Describe all statistical methods, including those used to control for confounding | 8 |
| | | (*b*) Describe any methods used to examine subgroups and interactions | 21-25 |
| | | (*c*) Explain how missing data were addressed | 21-25 |
| | | (*d*) If applicable, describe analytical methods taking account of sampling strategy | |
| | | (*e*) Describe any sensitivity analyses | 11 |
| **Results** | | | |

| | | | |
|---|---|---|---|
| Participants | 13* | (a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed | 9 |
| | | (b) Give reasons for non-participation at each stage | 9 |
| | | (c) Consider use of a flow diagram | |
| Descriptive data | 14* | (a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders | 9-10; 21-25 |
| | | (b) Indicate number of participants with missing data for each variable of interest | 11; 21-25 |
| Outcome data | 15* | Report numbers of outcome events or summary measures | 10-12;22-25 |
| Main results | 16 | (*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included | 2;10-11 |
| | | (*b*) Report category boundaries when continuous variables were categorized | |
| | | (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period | |
| Other analyses | 17 | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses | 11 |
| **Discussion** | | | |
| Key results | 18 | Summarise key results with reference to study objectives | 12 |
| Limitations | 19 | Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias | 12-13 |
| Interpretation | 20 | Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence | 12-14 |
| Generalisability | 21 | Discuss the generalisability (external validity) of the study results | 13 |
| **Other information** | | | |
| Funding | 22 | Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based | 3 |

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.