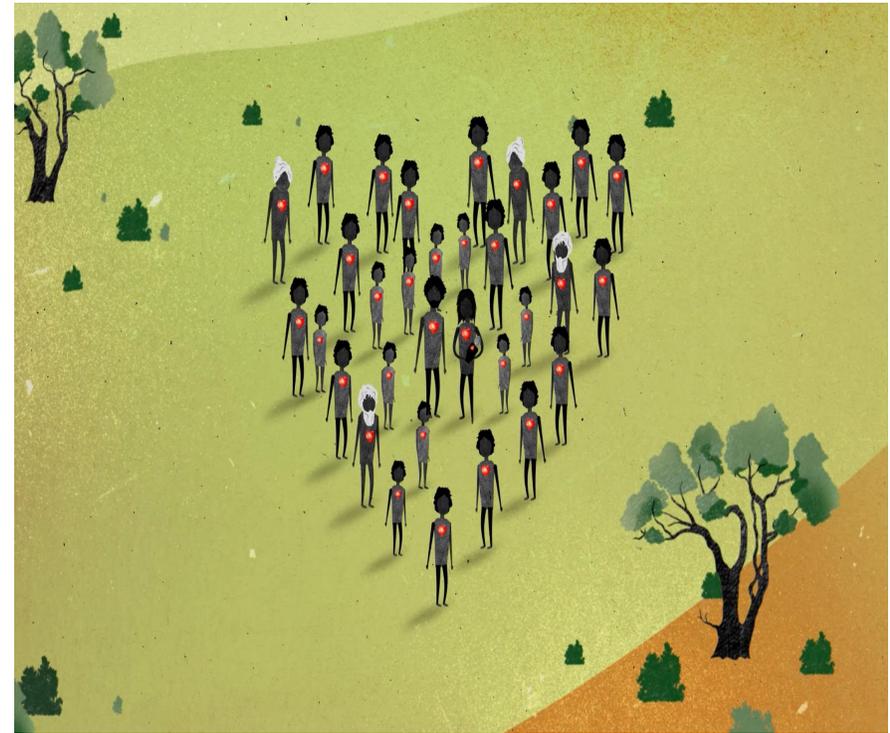


# Fetal Alcohol Spectrum Disorder Whole of Community Response



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DR MICHAEL DOYLE

DR ROBYN WILLIAMS

MR JIMMY PERRY

25 MARCH 2021

# Acknowledgements

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Dr Robyn Williams and Dr Sharynne Hamilton

Dr Janet Hammill, Dr Lorian Hayes, June Councillor, June Oscar & community of Fitzroy Crossing

Grandmothers & Aunties, Grandfathers, Uncles

Our families supporting and looking after family members with FASD

Our Aboriginal community controlled sector across Australia



**BECAUSE OF HER, WE CAN!**

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**8-15 JULY 2018**

## Aims of Workshop



Aboriginal and Torres Strait Islander women have led the way in addressing FASD in our communities. Is it time that Aboriginal and Torres Strait Islander men had a stronger role to support the valuable work and leadership by our women in FASD?

Change to  
workshop  
Due to COVID-19

## **FASD, a whole of community response**

The format of the workshop will be changed as both the Aboriginal women who were going to co-lead the workshop are unable to attend NIDAC due to workplace rules around traveling during the COVID-19 pandemic. For cultural reasons, as both the presenters are Aboriginal men, the focus will be on caring for boys and men who have fetal alcohol spectrum disorder.

## Definition of FASD

FASD – “a diagnostic term that describes the range of effects that can occur in an individual who was prenatally exposed to alcohol. These effects can include lifelong physical, mental, and behavioral difficulties, as well as learning disabilities...The vast majority of people with FASD are not visibly different, you cannot see FASD...the important fact is that...the function of the brain is permanently affected.” CanFASD Research Network

Online - <https://canfasd.ca/topics/basic-information/>

# Misconceptions of FASD

- **Must have physical facial features to identify FASD.** FASD is called the invisible disability as the majority (up to 90%) are born with no identifiable facial features
- **Children grow out of FASD.** FASD is a lifelong disability impacting across the lifespan requiring diagnosis, early intervention and support for a SAFE/quality of life
- **No point to diagnose FASD.** Diagnosis acts as a catalyst for services, and for families to adapt their parenting approaches and expectations. Also applies to every sector, education, child protection, health, AOD and criminal justice.
- **This is mainly an Aboriginal problem.** FASD is a serious global mainstream problem in every community without awareness of alcohol consumption during pregnancy.

# Ground Zero: Grandmothers & Aunties (2015)

## ***Grandmother raising two brothers from birth***

...Well I wish I did have a bit more support for them actually, but I never did. Because my husband was alive at the time so we did it together. The crying was an issue for the first 8 months. When we did ask for help, we didn't get it; some other excuse would come up saying they didn't do that now. The only thing DCP did provide was a washing machine and a fridge. Never did have respite offered at all.

## ***Aunty raising nephew from birth***

.....when DCP bought him to me they said he had FASD and that he probably wouldn't walk or talk, so throughout his whole life we have been in and out of PMH doing tests, fighting infections, checking brain waves

# Ground Zero: Grandmothers & Aunties (2015)

## ***Aunty caring for two brothers***

....by the time he left my care he needed a hug everyday from me, it was to make him feel good, telling him he was loved, and he was in the right place, and he was going to do well, and grow up and be brilliant. Always be positive, and that is all I had to give in the end, because I was so frustrated with the system, they really let me down, more importantly they really let them down.

## ***Aunty caring for two brothers***

.....The younger one in my care was supposed to get a hip replacement; he had bone on bone, crunching against each other, could you imagine a young man walking around in that kind of pain?

## ***Aunty raising nephew from birth***

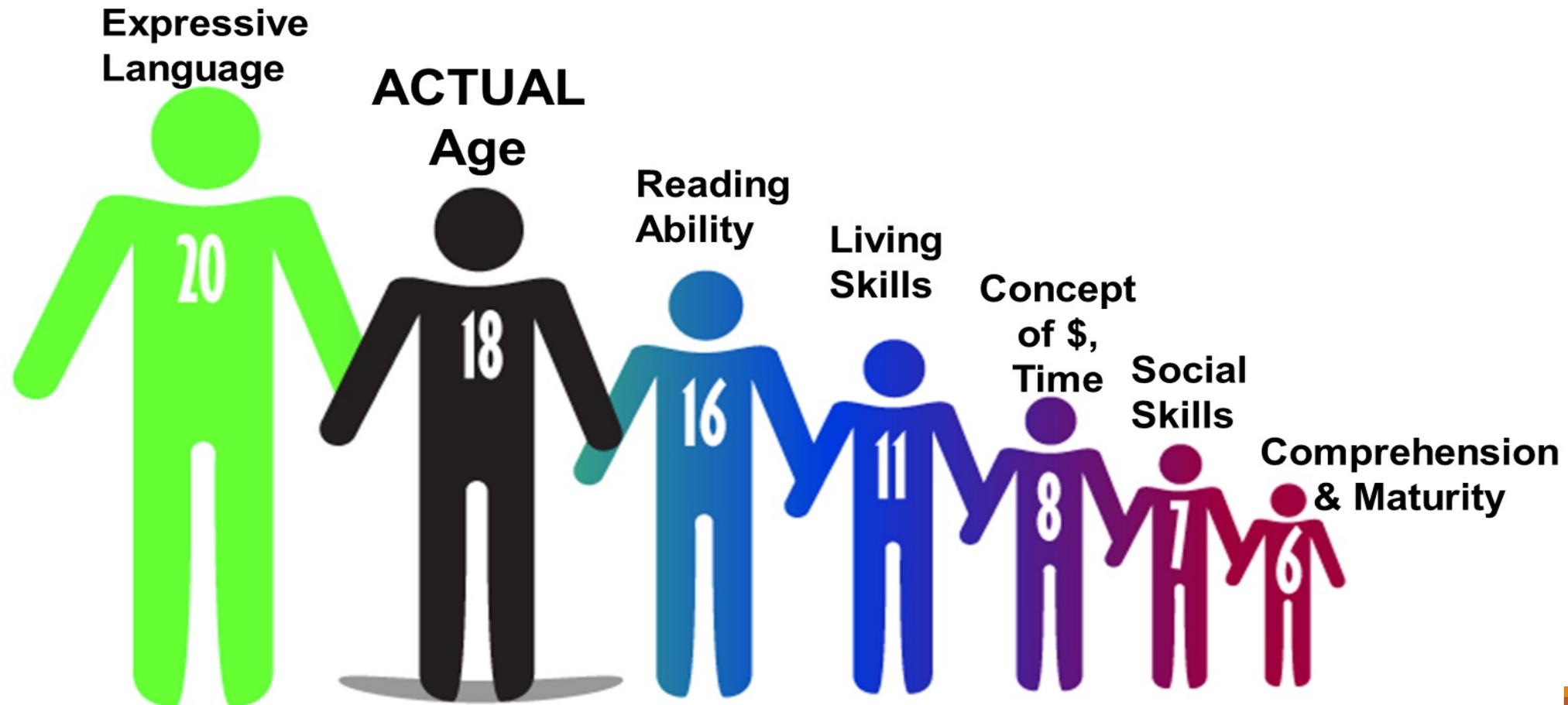
.....I don't think he will ever be able to have independent living, he can't problem solve, he doesn't have cognitive thinking. He works on impulse, so he does stupid things because he's not scared of anything. If someone told him to do something, he just does it. He is different, because his brain isn't at the 23 year old stage of maturity.

# Themes from Grandmothers & Aunties (Dr Robyn Williams PhD)

- ❖ Raising more than one sibling with FASD, none of the children were raised by their biological parents, and none of the families were provided with FASD training
- ❖ Kinship carers all experienced their own chronic health problems and this impacted on the placement (2 of the placements broke down due to chronic health issues of kinship carers)
- ❖ Receive less services (and financial support) than non-Aboriginal foster carers (supported by other studies on Aboriginal women) (Eades, 2020)

What you see is NOT where individuals are functioning...

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# Juvenile detention

Open Access

Research

## BMJ Open Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia

Carol Bower,<sup>1,2</sup> Rochelle E Watkins,<sup>1,2</sup> Raewyn C Mutch,<sup>1,2,3,4</sup> Rhonda Marriott,<sup>5</sup> Jacinta Freeman,<sup>1</sup> Natalie R Kippin,<sup>1,6</sup> Bernadette Safe,<sup>1,3</sup> Carmela Pestell,<sup>1,7</sup> Candy S C Cheung,<sup>7</sup> Helen Shield,<sup>7</sup> Lodewicka Tarratt,<sup>7</sup> Alex Springall,<sup>7</sup> Jasmine Taylor,<sup>7</sup> Noni Walker,<sup>1</sup> Emma Argiro,<sup>4</sup> Suze Leitão,<sup>1,6</sup> Sharynne Hamilton,<sup>1,3</sup> Carmen Condon,<sup>1</sup> Hayley M Passmore,<sup>1,3</sup> Roslyn Giglia<sup>1,2</sup>

**To cite:** Bower C, Watkins RE, Mutch RC, *et al*. Fetal alcohol spectrum disorder and youth justice: a prevalence study among young people sentenced to detention in Western Australia. *BMJ Open* 2018;**8**:e019605. doi:10.1136/bmjopen-2017-019605

► Prepublication history for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2017-019605>).

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Revised 4 December 2017  
Accepted 21 December 2017

### 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 10–17 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% CI 27% to 46%).

**Conclusions** This study, in a representative sample of young people in detention in Western Australia, has

### 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 fetal alcohol spectrum disorder.
- 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.

and decision making.<sup>1–3</sup> 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.<sup>4</sup> In the Fetal Alcohol Follow-up Study of

# Canadian research, FASD in adult prisons, community corrections

2011

2019



June 2011 | Number R 247

## Research at a glance

**Fetal Alcohol Spectrum Disorder (FASD) in a correctional population: Prevalence, screening and characteristics**

**KEY WORDS:** *Fetal Alcohol Spectrum Disorder (FASD), federal offenders, FASD Screening, FASD diagnosis, prevalence*

### Why we did this study

Research suggests that individuals with an FASD are more likely to have contact with the criminal justice system due to neuropsychological deficits in judgement, understanding consequences of behaviour and learning cause and effect. Although widely believed, there was no existing research examining the prevalence of FASDs among the general adult offender population.

The goal of this research was to determine the prevalence of FASDs among a sample of adult male offenders from the general offender population and to develop a screening tool for FASD to be used to flag offenders at risk for an FASD.

### What we did

The FASD Brief Screen Checklist (BSC) was developed and a diagnostic protocol piloted. During the 18 month study period all newly sentenced offenders at the institution, age 30 and under, were asked to participate in the research. Interviews were held with all offenders who met the inclusion criteria, and 65% agreed to participate. Each offender underwent a full medical assessment for FASD. Research Assistants in the community contacted family members to administer the BSC and asked questions regarding prenatal alcohol exposure. Once all data on each participant was collected, a case conference was held to determine if the offender met the criteria for a diagnosis in one of the FASD categories.

In particular, they were much more likely to have had previous incarcerations as juvenile offenders, and previous incarcerations in adult provincial facilities.

The properties of the BSC were analysed and the screening tool was found to be predictive of an FASD. Medical diagnosis was used as the gold standard to assess performance of the BSC.

### What it means

None of the offenders diagnosed in this study had been previously identified as having an FASD. There is a population of offenders within Correctional Service Canada who are affected by FASD who are currently not being recognized upon intake, and are not being offered the types of services or programs that meet their unique needs. This research has shown that adult male offenders with FASD have a higher severity of needs and are rated as higher risk as compared to offenders without FASD.

Screening to identify those at risk for an FASD is necessary and has been demonstrated as feasible in a correctional context. In addition, the medical and neuropsychological requirements of a diagnosis can also be successfully implemented with individuals incarcerated in an adult federal penitentiary.

### For more information

MacPherson, P.H., Chudley, A.F. & Grant, B.A. (2011)

McLachlan et al. *BMC Public Health* (2019) 19:43  
<https://doi.org/10.1186/s12889-018-6292-x>

BMC Public Health

## RESEARCH ARTICLE

Open Access



# Prevalence and characteristics of adults with fetal alcohol spectrum disorder in corrections: a Canadian case ascertainment study

K. McLachlan<sup>1\*</sup>, A. McNeil<sup>2</sup>, J. Pei<sup>2</sup>, U. Brain<sup>3</sup>, G. Andrew<sup>4</sup> and T. F. Oberlander<sup>5</sup>

## Abstract

**Background:** Individuals with fetal alcohol spectrum disorder (FASD) experience a range of cognitive, affective, and physical deficits following prenatal alcohol exposure. They are thought to be overrepresented in criminal justice settings. However, limited evidence is available to inform prevalence. We sought to estimate the prevalence of FASD in a Northern Canadian correctional population.

**Methods:** Using an active case ascertainment approach we recruited a representative sample of 80 justice-involved adults (ages 18–40, 85% male) over an 18-month period from 2013 to 2015. Participants completed interdisciplinary clinical assessments comprising medical and psychological evaluations that adhered to the 2005 Canadian FASD Diagnostic Guidelines.

**Results:** We identified a high rate of FASD (17.5, 95% CI [9.2, 25.8%]) in this sample, and this rate could have been as high as 31.2% with confirmation of prenatal alcohol exposure. Most participants in this study presented with significant neurodevelopmental and cognitive deficits in at least two domains of functioning, irrespective of diagnosis, with only five of 80 participants (6.3%) demonstrating no cognitive impairment.

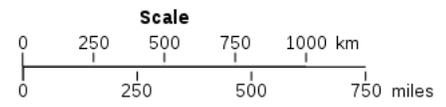
**Conclusions:** Findings showed disproportionately high estimated FASD prevalence in this representative sample compared to general population estimates in both Canada and the U.S. (2–5%), underscoring the need for improved FASD screening and diagnosis in correctional settings, and education for clinicians working in the justice context. Strengthened health prevention and intervention efforts to support the needs of individuals with FASD outside the criminal justice context are needed.

**Keywords:** Fetal alcohol spectrum disorder, Prevalence, Criminal justice, Correctional, Prenatal alcohol exposure



**CANADA – Political**

- International border
- - - Provincial/territorial border
- Alberta** Province/territory
- ★ **Ottawa** National capital
- ★ **Regina** Provincial/territorial capital



# Summary: Criminal justice system

- ❖ 2018 Banksia Hill some form of cognitive disability 89%
- ❖ 2018 Banksia Hill diagnosed with FASD 36%
- ❖ 2019 Canadian FASD study, adults in prison or community orders (remote) 9.9%
- ❖ 2011 Canadian FASD study, adults in prison (remote) 17.5%
- ❖ No study in Australia of FASD in adults prison system

# Cultural Safety Framework on FASD & Disability

Aboriginal people with FASD continue to be in an unsafe position as they live with this disability undiagnosed and unsupported. Whilst there is significant Australian evidence on FASD in the Aboriginal community this should now translate to a call for action, and cultural safety framework on FASD & Disability across all sectors that are Aboriginal led; including

- ❖ Health, child protection, education and criminal justice
- ❖ FASD Interventions led by the Aboriginal Community Controlled Sector
- ❖ AOD treatments
- ❖ FASD Training

# Workshop questions

- ❖ What needs to happen to improve the lives of families affected by FASD?
- ❖ What health and other services *or research* is needed?
- ❖ Is there need for the development of a cultural care framework?

*Thank you*

*If you want to contact anyone involved in the workshop  
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*michael.doyle@sydney.edu.au*

*jimmy@adac.org.au*

F A S D A W A R E N E S S D A Y - 9 / 9

# Fetal Alcohol Syndrome Average Life Expectancy

# 34

*Early diagnosis & proper support create brighter futures*

**We're fighting for our kids' lives**



[FASDLearningWithHope.wordpress.com](http://FASDLearningWithHope.wordpress.com)

@FASD\_Mum @FASD\_Dad

Affiliated with @FASD\_UK

Source: <http://www.ncbi.nlm.nih.gov/pubmed/26962962>