Today’s webinar on ‘Prevalence of FASD among youth under the care of Juvenile Justice in Western Australia: how shall we work together to close this gap? with guest presenter Dr Raewyn Mutch will be starting at 10am W.S.T.

Here are some tips for when the webinar starts.

If you are having difficulties with video quality

- close all other applications running on your computer including email, instant messenger, browsers etc.
- check the bars at the top right hand corner of the Adobe screen – if they are green then internet connectivity is good, if they are white your video will be frozen due to a poor internet connection

If you are having difficulties with sound quality

- try using headphones for better audio
- ensure volume is turned up on your computer
- ensure your speakers are turned on in the Adobe Connect webinar window

If problems still persist we recommend you logout of this session then log back in

Feel free to use the ‘chat’ box to ask questions if you are having difficulties.
Prevalence of FASD among youth under the care of Juvenile Justice in Western Australia: how shall we work together to close this gap?

Presenter: Dr Raewyn Mutch

*If you are having technical difficulties check the trouble shooting tips in the chatbox

**This webinar is being recorded and will be added to our website. It will include any typed comments you include
I acknowledge Aboriginal and Torres Strait Islander people as the traditional custodians of our land.
I acknowledge the Wadjuk people of the Nyoongar Nation
The traditional owners of the *Wadjak boodjar* (Perth land) near near the *Derbal Yerrigan* (Swan River).

- *kaya* = hello
- *wanju* = welcome
- *nidja/yimniny* = here
- *djurapin* = happy
- *nyininy/nyin* = sit
- *nih/ni* = listen
- *kaartdijin* = knowledge, learn
Only some of this is our story to tell.

We must always look to tell stories of Hope

Raewyn Mutch
Clinical Associate Professor
with the Banksia Hill Study Team
Telethon Kids Institute
Princess Margaret Hospital for Children
Alcohol is a teratogen - interrupts or alters the normal development of a fetus, including the development of the brain or other major organs.
Animal Studies

- Dr K Sulik and team, University of North Carolina

- Limitations of animal studies
How much alcohol?

• We don't know how much alcohol, if any, is safe to drink during pregnancy

• Evidence; **risk of harm to the fetus is greater the more alcohol the mother consumes**

• Evidence: **binge drinking is harmful**

• Not all children exposed to alcohol during pregnancy will be affected or affected to the same degree

• The level of risk to the fetus is hard to predict – broad range of effects are possible
How much alcohol?

- **Timing** (*gestation*) When during the development
- **Frequency** (*throughout pregnancy*) How often was there exposure
- **Quantity** (*at each exposure*) How much alcohol at each exposure

*Fetal Growth From 8 to 40 Weeks*
“Of all the substances of abuse, including cocaine, heroin, and marijuana, alcohol produces by far the most serious neurobehavioral effects in the fetus.”

*IOM Report to Congress, 1996*
NHMRC Guideline 4:

- Maternal alcohol consumption can harm the developing foetus or breastfeeding baby.
- For women who are pregnant or planning a pregnancy, not drinking is the safest option.
- For women who are breastfeeding, not drinking is the safest option.
47% consumed alcohol before knowing they were pregnant

26% continued drinking alcohol after knowing they were pregnant

National Drug Strategy Household Survey 2013
Embryology

5 weeks
- Frontonasal prominence
- Nasal pit
- Maxillary prominence
- Mandibular prominence

6 weeks
- Nasal pit
- Lateral nasal prominence
- Medial nasal prominence
- Nasolacrimal groove
- Stomodeum

8 weeks
- Lateral nasal prominence
- Medial nasal prominence
- Maxillary prominence
- Mandibular prominence
- Nasolacrimal groove
- Eye

10 weeks
- Eye
- Nasolacrimal groove
- Philtrum

Please do not copy or distribute this photograph without permission from Susan Astley, Ph.D.
Palpebral Fissure Length

Lip Circularity
Embryology of the Brain

http://www.youtube.com/watch?v=Li5nMXg1Lk
Fetal Alcohol Spectrum Disorder?

Severe pervasive neurodevelopmental impairment attributable to prenatal alcohol exposure.

FASD in Australia has 2 sub-categories:

- FASD with 3 sentinel facial features
- FASD with < 3 sentinel facial features

Australian Guide to the Diagnosis of FASD [http://alcoholpregnancy.telethonkids.org.au/]
Australian FASD diagnostic criteria

Prenatal alcohol exposure + 3 sentinel facial features OR 0, 1 or 2 sentinel facial features + Neurodevelopmental impairment in 3+ domains
Sentinel Facial Features

The majority of people with FASD will not have these facial features:

- Palpebral fissures (short eye openings)
- Smooth philtrum (space between nose and upper lip)
- Thin upper lip
Most children with FASD have typical facial features

Non-typical behaviours

- Inconsistent
- Mimic conditions you may be familiar with
How common is FASD?

FASD exists among people from all racial backgrounds.

International
- 0.2 to 5 per 1000
- 135.1 to 207.5 per 1000 early school age children in Sth. Africa

Western Australia
- 120 per 1,000 just for FAS Fitzroy Valley, Australia
Diagnosis

Diagnosis of FASD requires assessment by a range of clinicians

‘Gold standard’ approach:

• Paediatrician
• Neuropsychologist/psychologist
• Speech Pathologist
• Occupational Therapist

Australian Guide to the Diagnosis of FASD
Impairment + Disability
Difficulties which can result from FASD

- Behaviour problems
- Speech and language difficulties
- Memory and learning difficulties
- Cognitive problems
- Executive functioning problems
- Motor difficulties
- Impulsivity and Hyperactivity
- Sensory processing difficulties
- Features of Autism

Can lead to

- Secondary problems
- School failure
- Mental health issues
- Drug and alcohol problems
- EARLY Engagement with the justice system
  - both as witness
  - and as offender
“These behaviours are not intentional; they are the result of permanent brain damage.”
Consequences of undiagnosed FASD

- Consequences of undiagnosed FASD
  - Broad and far reaching effects

- Undiagnosed FASD adversely affects their development
  - Loss of education
  - Loss of opportunities

- In turn affects whole families and the wider community
  - Increased costs of health
  - Increased costs of welfare services
  - Reduced educational opportunities
  - Reduced employment
  - EARLY ENGAGEMENT WITH JUVENILE JUSTICE
Consequence of early engagement with juvenile justice (ABS statistics)

• Consequences of youth offending and youth victimisation
  • Broad and far reaching effects

• Youth victims and youth offenders have adverse effects on development
  • Loss of education
  • Loss of opportunities

• In turn affects whole families and the wider community
  • Increased costs of health
  • Increased costs of welfare services
  • Reduced educational opportunities
  • Reduced employment
FASD and risk for Incarceration

Previously no data on FASD among young people in detention in Australia

Internationally:
23% youth in juvenile detention had a diagnosis of FASD
19x greater risk of incarceration among youth with FASD
60% of youth with FASD had previously had contact with the law

Nov 23 2017; Yukon corrections population
• 17.5% prevalence
• % much higher if could obtain history of alcohol exposure
The Banksia Hill Project

A feasibility study of screening, diagnosis and workforce development to improve the management of youth with fetal alcohol spectrum disorder in the justice system

Funded by: National Health and Medical Research Council (NHMRC)
Ethics approvals: WA Aboriginal Health Ethics Committee, University of WA Human Research Ethics Committee
Acknowledgements

The children and young people at Banksia Hill and their families and carers

Banksia Hill Detention Centre staff

National Health and Medical Research Council

Department of Justice (formerly Department of Corrective Services)

Department of Communities (formerly Department for Child Protection and Family Support)

Community and Other service providers

DISCLAIMER: This research is conducted with the assistance of the Western Australian Department of Justice and the Department of Communities. Materials published or presented as part of this project are neither endorsed by either department, nor are an expression of the policies or view of the departments. Any errors of omission or commission are the responsibility of the research team.

The images in this presentation are for information purposes only. The researcher makes no representations as to the accuracy or completeness of any images provided in this presentation. The images are not endorsed by the Department of Justice and do not show department facilities, infrastructures or people in care.
Existing Community Consultations

**Government**
- WA Police
- Child Safety Directors
- Youth Justice Forum
- Commissioner for Children and Young People.
- DCPFS Meekathara
- South Metro Public Health Unit-Aboriginal Health team

**Office of the Inspector of Custodial service** – Joseph Wallam
**Drug and Alcohol Youth Service** (DAYS) – Banksia Hill counsellor

**Successive Government Ministers** and their staff across
- Corrective Services
- Child Protection
- Health
- Education
- Communities

**Consumer Reference Group**
- Neil Reynolds and Aaron Dick
- Beverley Colbridge and Robyn Williams

**Stakeholders and Community Organisations**
- Aboriginal Legal Services
- Legal Aid
- Derbal Yerrigan – Barbara Henry
- Noongar Patrol
- Aboriginal Alcohol Drug Service
- Jacaranda Community Centre
- Champion Lakes, Armadale
- Noongar Outreach
- Aboriginal Alcohol and Drug Service
- Jacaranda Community Centre
- Koya Aboriginal Corporation
- Mission Australia - (DAYS)
- Noongar Radio
- Nguna Morrt Aboriginal Corporation
- OVAHS, Kununurra
- GRAMS – Arthur (Sandy) Davies
- Pindi Pindi
- Winjan Aboriginal Corporation

**Banksia Hill**
- BHDC Aboriginal Welfare Reference Group
- Aboriginal Visitors Scheme
- TKI Aboriginal Reference Group (internal)

**Steering Group**
Representatives from:
- First Peoples Disability Network Australia
- National Organisation for FASD Australia (NOFASD)
- Aboriginal Legal Service WA
- Office of the Inspector of Custodial Services
- Banksia Hill Detention Centre
- Consumer Representatives
- Chief investigators & project team

**Quote**
"IF WE DON'T STAND UP FOR CHILDREN...THEN WE DON'T STAND FOR MUCH"  - MARIAN W. EDELMAN
Banksia Hill Project Team

PROJECT TEAM
Telethon Kids Institute
• Noni Walker
• Raewyn Mutch
• Sharynne Hamilton
• Jacinta Freeman
• Hayley Passmore
• Natalie Kippin
• Bernadette Safe
• Carmen Condon
• Candy Cheung*
• Vicole Bothma*
• Helen Shield*
• Jasmine Taylor*
• Alex Springall*
*Supervised by C. Pestell UWA

CONSUMER REFERENCE GROUP
• Neil Reynolds
• Aaron Dick
• Beverley Colbridge
• Robyn Williams

CHIEF INVESTIGATORS
• Professor Carol Bower, Telethon Kids Institute
• Dr Rochelle Watkins, Telethon Kids Institute
• Professor Rhonda Marriott, Murdoch University
• Clin Assoc Prof Raewyn Mutch, Telethon Kids Institute

ASSOCIATE INVESTIGATORS
• Professor Steve Zubrick, Telethon Kids Institute
• Mr Peter Collins, Aboriginal Legal Service WA
• Assoc Prof Carmela Pestell, UWA & Telethon Kids Institute
• Dr James Fitzpatrick, Telethon Kids Institute
• Professor Jonathan Carapetis, Telethon Kids Institute

STEERING GROUP
Representatives from:
• First Peoples Disability Network Australia
• National Organisation for FASD Australia (NOFASD)
• Aboriginal Legal Service WA
• Office of the Inspector of Custodial Services
• Banksia Hill Detention Centre
• Consumer Representatives
• Chief investigators & project team
The Banksia Hill Project

Objectives:

1. Estimate the prevalence of FASD in an Australian youth justice context
2. Workforce development – Intervention for custodial staff
3. Qualitative evaluation of the impact of the research project
Banksia Hill Detention Centre

- The only youth detention facility in WA
- Youth on remand & sentenced
- Males and females
- Current population ~150-160
Only youth-detention centre, Western Australia

- Between May 2015 and December 2016
- Aged 10 to 18 years and 94% male

73% are Aboriginal and Torres Strait Island young people
The Banksia Hill Project

Assessment team – ‘gold standard’

- Paediatrician
- Occupational Therapist
- Speech Pathologist
- Neuropsychology team
- Research Officer

Eligibility

Young people who were:

• Aged between 10 years and 17 years 11 months
• Sentenced to detention at Banksia Hill Detention Centre
• Sentenced to a minimum two week period
• Written assent from the young person
• Written consent by responsible adult
• Final approval for participation by BHDC
Participants

- 166 young people invited to participate in research
  - 12 declined
  - 41 assented with no consent
  - 113 assented and consented

- 99 underwent full assessment for FASD ($n$)
- 95% males
- Average age 16 years
Where did these young people come from?

- Aboriginal Australian: 73%
- Other Australian: 16%
- New Zealand, Maori & Cook Islander: 6%
- Middle East, Africa & Asia: 5%
- Self identified ethnicity of participants: 52%
Many of these young people are a long way from home
Biomedical and Psychosocial Interview

Young person:
• Hobbies
• Sports
• Substance misuse
• Schooling
• Admissions to detention
• Some trauma

We never asked their offence
Proximal Interviews

Parent/caregiver:
• Conducted usually via phone and sometimes from more than one source
• Modified survey to collect
  – birth, developmental, schooling, hospitalisations history
  – prenatal alcohol exposure information using the Audit-C
Challenges

• Environmental limitations

• Lack of adaptive functioning assessment due to nature of setting

• Tension between forensic vs clinical/advocacy role within a research context

• Lack of real life setting to conduct assessment
NP test battery (2 hrs total)

- Wechsler Abbreviated Scale of Intelligence – 2nd Ed (WASI-II)
- Or Wechsler Non-Verbal Scale of Ability (incl. spatial span)
- Delis-Kaplan Executive Function System (DKEFS):
  - colour-word interference
  - trail making
  - category fluency
- WRAML-II Screening Memory Index
- Wide Range Achievement Test (WRAT-4):
  - reading comprehension
  - word reading
  - sentence comprehension
  - spelling and math computation

1. BRIEF (Teacher)
2. Child Behaviour Checklist (Teacher)
3. Vineland-II (Teacher)
4. Lifeskills Checklist
List domains from highest to lowest prevalence of impairment

- Cognition
- Attention & Processing Speed
- Motor
- Language
- Academic Achievement
- Executive Functioning
- Memory
## Prevalence of Impaired Domains - Preliminary

<table>
<thead>
<tr>
<th>Domain</th>
<th>All participants %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Academic Skills</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Executive Functioning</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Attention &amp; Processing Speed</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Language</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Memory &amp; Learning</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Motor Skills</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Cognition</strong></td>
<td></td>
</tr>
</tbody>
</table>
Of those with FASD, list domains from highest to lowest prevalence of impairment

- Cognition
- Attention & Processing Speed
- Motor
- Language
- Academic Achievement
- Executive Functioning
- Memory
Our World-First study

- Representative sample

- Significant % have at least one severe neurocognitive impairment
Physical and Mental Health

Vision and Hearing
Dentition and Diet
Metabolic and Musculoskeletal
Opportunity and Learning
Place and Mastery
Trauma and Choices
Hope and Grief
Language, FASD & Youth Justice
The true measure of our character is how we treat the poor, the disfavored, the accused, the incarcerated and the condemned.

We are all implicated when we allow other people to be mistreated.

Bryan Stevenson  Just Mercy
Cost of youth justice - 2015-2016

- $731.9 million nationally on youth justice supervision
- $1428.43 per day per young person in detention - National average
- $360,000 per year per young person in detention - Western Australia
Aboriginal and Torres Strait Islander Children and Adolescents

AIHW 2015-16 (2011-12)

• 25 (21) times more likely to be in detention

• 17 (13) times more likely to be under some form of youth justice order

• than non-Indigenous children.
More than 100 legal and community organisations have written to Malcolm Turnbull demanding a national solution to the Indigenous youth incarceration rates.

“This is a national crisis, which demands an immediate national response”
3 juvenile justice workers injured while trying to break up a fight between inmates at the Frank Baxter Juvenile Justice Centre (NSW)

Victorian youth justice centre deemed 'appalling' 6 years before riot crisis, serious problems were flagged with successive governments for more than a decade ...the recent dysfunction is the result of years of inaction. (15 inmates broke out of the Malmsbury Youth Justice Centre).
• Outcry over capsicum spray, authorisation of tear gas to break up a fight

WA's Corrective Services Commissioner James McMahon said: "We are seeing the same amount of incidents but over the three years that we’ve put the reforms in place (since 2013) we’ve been able to manage and contain the incidents," He said many of the children in the centre have foetal alcohol spectrum disorders and methamphetamine in particular, was now a problem.

Substantiated misconduct allegations against staff at Queensland's 2 youth detention centres have more than tripled in the past year.

Attorney-General Yvette D'Ath is broadening the terms of reference handed to the Youth Detention Review Commission (Queensland) and extending the timeframe for submissions.
"THE TROUBLE IS THAT ONCE YOU SEE IT, YOU CAN'T UNSEE IT....."

ARUNDHATI ROY.
"...AND ONCE YOU'VE SEEN IT, KEEPING QUIET, SAYING NOTHING, BECOMES AS POLITICAL AN ACT AS SPEAKING OUT. THERE'S NO INNOCENCE. EITHER WAY YOU'RE ACCOUNTABLE."

ARUNDHATI ROY.
"IT'S EASIER TO BUILD STRONG CHILDREN, THAN TO REPAIR BROKEN MEN."

FREDERICK DOUGLASS.
Australian Human Rights Commission

“This is a Once-in-a-Generation Opportunity.”
"YOU MAY CHOOSE TO LOOK THE OTHER WAY BUT YOU CAN NEVER AGAIN SAY THAT YOU DID NOT KNOW."

WILLIAM WILBERFORCE.
Protect the right to receive specific protection and care when vulnerable and from a high risk population.

1. United Nations (UN) Convention on the Rights of the Child (CRC);
2. UN Declaration on the Rights of Indigenous Peoples;
3. UN Convention on the Rights of Persons with Disabilities;
4. UN Rules for the Protection of Juveniles Deprived of their Liberty;
5. UN Standard Minimum Rules for the Administration of Juvenile Justice (Beijing Rules); and
“in order to treat some persons equally, we must treat them differently”
Diversion

UWA Law School
• Professors Harry Blagg and Tulich

White Ribbon and Healing Foundation

Kimberley Stakeholders

Pilbara

Kalgoorlie

Amnesty International
Respectful Relationships and Partnerships

- Department of Corrective Services
- Lead Aboriginal Community Organisations
- National Collaborations
- International Collaborations
Development of training resources

- Hayley Passmore  mailto:hayley.passmore@telethonkids.org.au

- A series of videos for each of the domains assessed

- Focus on strategies specific to each domain

- Include perspectives from:
  - Custodial staff
  - Young people in detention
  - Young people with impairments
  - Families and carers
  - Health professionals
Towards an Aboriginal and Torres Strait Islander violence prevention framework for men and boys

Go Listen, Ask, Hunt for People and Resources.......  

https://www.menzies.edu.au/page/Research/Projects/Mental_Health_and_wellbeing/E-mental_health_support_for_Indigenous_clients/  

http://resources.menzies.edu.au/download/Yarning_About_Mental_Health_flip_chart.pdf
Funding to enable national summit and count the difference

Collaborative community-led and designed path to healing and hope

Insanity: doing the same thing over and over again and expecting different results.

- Albert Einstein

We cannot solve our problems with the same thinking we used when we created them.
Australia’s online FASD Hub

1. https://www.fasdhub.org.au

2. https://www.youtube.com/watch?v=qO5YFS7YQ8w&feature=youtu.be

Videos of children and families

Videos funded through the Hedland FASD Project (BHP)

• Making FASD History in the Pilbara Tracy’s story  https://vimeo.com/232621789
• Making FASD History in the Pilbara Sissy’s story  https://vimeo.com/232767831
• Making FASD History in the Pilbara Alfred’s story  https://vimeo.com/232767673

Videos funded through the Marulu FASD Prevention Strategy (WA DoH)

Children with FASD - Alex’s story  https://www.youtube.com/watch?v=sEKj44apkLc&feature=youtu.be
Children with FASD - Lillie’s story  https://www.youtube.com/watch?v=0p7O4TSk5sg&feature=youtu.be
Children with FASD - Sharon’s story  https://www.youtube.com/watch?v=tMSmIKicaJA&feature=youtu.be
Mo tatou a mo ka uri a muri ake nei: "For us and our children after us."
<table>
<thead>
<tr>
<th>Perception</th>
<th>Actual Situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immature</td>
<td>Doesn't understand social cues and rules</td>
</tr>
<tr>
<td>Thief</td>
<td>Doesn't understand ownership</td>
</tr>
<tr>
<td>Doesn't get the obvious</td>
<td>Needs many re-teachings, doesn't understand, despite intelligence</td>
</tr>
<tr>
<td>Makes the same mistakes</td>
<td>Can't link cause to effect, can't see similarities, has difficulty generalizing</td>
</tr>
<tr>
<td>over and over</td>
<td></td>
</tr>
<tr>
<td>Doesn't work independently</td>
<td>Has chronic memory problems, can't translate verbal directions into action</td>
</tr>
<tr>
<td>Is overly physical</td>
<td>Is hyper- or hyposensitive to touch, doesn't understand social cues regarding boundaries</td>
</tr>
<tr>
<td>Uses poor social judgment</td>
<td>Not able to interpret social cues, needs help organizing</td>
</tr>
</tbody>
</table>
Diagnosis allows for Reframing

- Disobedient
- Lies
- Late
- Tired
- Restless
- Attention
- Physical
- Immaturity
- Poor judgement
- Steals
- Infuriating on purpose
- Repeated mistakes

- Short Term memory
- Memory and verbal processing
- Time Organisation
- Circadian rhythm
- Sensory seeking
- Hyper and hypo
- Social cues
- Risk taking and at risk
- Ownership
- Failure to generalise
- Culmination of all above

[http://fasdjustice.ca/what-works/reframe-behaviours.html](http://fasdjustice.ca/what-works/reframe-behaviours.html)
Strategies for Success

• Parent-Carer-Centred Practice Based
• **Reframe** the way we look at behaviour

- OBSERVED BEHAVIOUR
  Problem behaviour

- REFRAME
  What is the underlying brain dysfunction?

- RESPONSE
  Respond to REASONS for behaviour

- REINFORCE
  REPEAT
  REMEMBER
  Impaired learning
  Impaired ability to generalise
Executive Function
The brain’s ability to take in information, interpret this information, and make decisions based on this information.

Planning

Organizing

Shifting Attention

Multi-Tasking

Challenges
How to Systematically Approach a Task
How to Break Down a Task into Smaller Steps
How to Manage and Organize Time
How to Complete a Task

Executive Function
Strategies

- Teach How to Ask for Help
- Give One Instruction at a Time
- Point Out the Important Information
- Use Clear and Direct Language
- Prioritize by Importance
- Create a reasonable Time Line or Due Dates
- Know what Works for Your Student and Stick with it

Adapted from:
Asperger Syndrome and Adolescence
By Brenda Smith Myles, Diane Adreon
Knowledge Centre FASD portal
http://www.aodknowledgecentre.net.au/aodkc/alcohol/fasd

FASD Hub Australia
https://www.fasdhub.org.au/
Contact details

Dr Raewyn Mutch
Email: Raewyn.Mutch@health.wa.gov.au

Australian Indigenous Alcohol and Other Drugs Knowledge Centre
Ph: (08) 9370 6336
Avinna’s email: a.trzesinski@ecu.edu.au
Email: aodknowledgecentre@healthinfonet.org.au