



Advancing FASD Research Together Research Symposium Workshop

27th October 2016

FASD Research Australia Centre of Research Excellence

2016 marks the beginning of a national coordinated approach to advancing FASD research capabilities in Australia



The inaugural Research Symposium for the FASD Research Australia Centre of Research Excellence (the Centre) was held in Perth on the 27th of October 2016.

The Symposium was attended by 45 delegates with 21 delegates participating in the Centre Scientific, Capacity Building and Consumer Committee meetings on the day before. WA Government representatives and stakeholders from the Justice, Education, Disability, Health and Child Protection sectors attended as well as representatives from NOFASD and research leaders from across Australia. Attendance numbers were strictly limited for this event as the Centre leaders wanted to encourage open dialogue during the day and enable the entire group to participate.

The program was a mix of short presentations highlighting current FASD-related research in Australia as well as discussion and workshops within our three focus areas: **Prevention, Diagnosis and Therapy.**

During the afternoon workshop, attendees were divided into these three focus areas, then further again into two tables. For each focus area, the first table scoped specific projects identified earlier while the second table put forward new ideas for future research. This document summarises outcomes from this workshop.

Event Details

Advancing FASD Research Together – Research Symposium 2016
Thursday 27th October
8.00am – 4.30pm
Telethon Speech and Hearing Centre
36 Dodd Street, Wembley, Western Australia [view map on Google](#)



Prevention Issues and Research Ideas

Empowering Women to Plan Ahead

- Strategies that empower women so that they can go to their antenatal appointments informed
- Focus on family planning; targeting women prior to pregnancy
- Free contraception & education
- Research of WHY there are so many unplanned pregnancies – why don't women plan?
- Addressing younger women and alcohol in general
 - sex education
 - contraception
- Unplanned Pregnancy
- Red flag alert when prescription for oral contraceptive not completed/repeated
- Compare knowledge and activity around drinking
- IF Stopping Contraception THEN
 - App to do AUDIT-C based on score then possible referral
 - Sent or given a pamphlet
 - Population of young women who are not planning pregnancy but could get pregnant refer to either the AUDIT-C app group above (1x) or Control.
- Six month pregnancy and drinking, drinking behaviour and knowledge need to be considered

Young Champions/Advocates

- Get health promotion messages on popular media eg integrate in Home and Away story line
- Triple J
- Magazines

Aligning Health Campaigns

- Alcohol needs to be repositioned – blue cheese is conveyed as more harmful!!
- Research on what information is provided to women in public and private agencies.
- Targeting messages that are clear about FASD....this is WHAT IT IS....this is LIFELONG and EVERYONE is at risk
- Tagging onto other health campaigns such as Breast Cancer (linked to alcohol and have positive branding)
- Marketing opportunities similar to breast cancer, red nose day etc – whoever alcohol prevention is (cancer, diabetes, heart etc) also include FASD messages
- Share health promotion messages

Engaging Men

- How do we engage?
- If they aren't engaged, why not? This includes prospective fathers.

Use of Social Media and Apps

- How do we use social media more effectively?
- Development of an App that has everything in it (healthy eating, smoking, obesity, BMI, drinking, pap smears, STIs)
- Track information on app eg Audit-C data
- App – when period is due, vaccinations due....what else?
 - Start at age 15/16 years
 - Sends alerts

Important Role of Maternal Services

- Maternal and Child Health Nurses at milestones
- Connecting with networks such as Midwives

Awareness via Education Sector

- ADHD – rise in ADHD in our society Assessment/Dx in main stream education (Phillip May's work AEDI) Australia Early Development Index
- Educational Raising Awareness

Future Research Ideas

Use of technology (social media/apps) in prevention

Understanding unplanned pregnancies

How do we engage men in prevention?

Advocacy Opportunities

Prevention campaigns and leveraging other community health messaging

Identification of a young champion for the cause

Raising awareness of FASD prevention in the Education sector



Diagnosis Issues and Research Ideas

Awareness

- Because of the high rates of FASD among children in care, and among youth in the justice system, screening for neurodevelopmental conditions including FASD should be carried out upon a child coming to the attention of CPFS, and upon a young person coming into contact with the justice system.
- Helpful ways to identify and know to be alert to the possibility of FASD.
- Training of issues that suggest FASD.
- Judicial training issue.
- To just identify that FASD is a potential issue that is flagged in the court by a clinic attached to the court.
- Process for flagging or follow-up.

Screening

- Screening tools needed for different areas (e.g., justice, schools)
- Children at risk (i.e., with known exposure to alcohol during pregnancy) need to be monitored/ followed and early intervention provided (e.g., midwives should flag children for paediatric follow-up).
- Information from birth records: If alcohol exposure could be kept on birth records, the CHN can be trained to use this information to initiate a conversation with women in the early post-partum period (a way to use information from midwives).
- How to keep track of information and data that is gathered.
- Children in the justice system: So many of the high risk group are in care so that when first entering care, assessments should be done.
- If DCP gets the information early, without invasion of privacy, from the child health clinic to identify at risk children before waiting for flagged behaviours to occur.
- Marker for screening?
- Biomarkers.

Referral

- Tapping into services and how to follow-up in early post-partum period, particularly in remote areas and communities.

Diagnostic service

- Difficulty with diagnosing children < 1 year of age without facial features. Developmental delay can be diagnosed without facial features.
- Being seen as accessible: providing and seeking information, consent from parents, etc.
- Need is high for FASD assessment. How to cope with demand?
- Development of Australian norms for facial assessment and diagnosis – is this necessary?
- The new diagnostic domains: affect regulation measures need to be developed in young children and infants such as feeding, sleeping and settling (see current guide – mostly refers to adult disorders).
 - What other things should we be measuring (in regards to affect regulation, which is poorly defined)?
 - Affect regulation: What does it mean? How is it measured in children < 10 years of age?
- Legislative change to children's and community services Act in every state for the children's court to have access to multi-disciplinary clinic to do reports quickly when necessary (Victoria has a children's court clinic – similar principle to include FASD within this idea).
- Free, comprehensive assessment for all youth who come into contact with youth justice.

Support for parents

- Identify parents who may have FASD (to enable the meeting of their needs).
- Parents are often missed (parenting programs need to be tailored to FASD).

Support for others

- What are the procedures for managing a child who does not quite meet the criteria for a FASD diagnosis?
- Academic unit through which trainee neuropsychologists, OTs etc. could enable more diagnoses to be made.
- Consider training some students in diagnostic assessment?
- Member of diagnostic team (neuropsychologists vs. psychologists)



Diagnosis Issues and Research Ideas cont.

Data sharing

- Enable data sharing with DCP and similar government agencies.
- Information sharing is sometimes difficult between government agencies in relation to child history.
- A lot of education in regards to sharing information is in the best interest of the child.
- Agreed process for sharing reports between sectors.
- Agreed process for accessing prenatal alcohol information between sectors.
- Pregnancy information is shared.

Covering costs

- Medicare item for FASD assessment issues:
 - long/short consultations
 - for allied health assessments
 - does not cover neuropsychologist assessment
 - multi-disciplinary teams
- Medicare funding for practice nurses for specialists.
- Write to Bruce Robinson who is reviewing Medicare numbers?
- Can clinicians claim sections of their FASD assessment through Medicare?
- Service provision being built into “system” (e.g., existing CDUs) to enable easier access to assessments/reduced costs.
- Pooled data: economic analysis (develop an app for parents to track expenses relating to living with FASD).
- Consider again the categories for disability support and how these match to the domains of impairment to consider then that the right interventions, service and support are being provided by the NDIS
- Modifying Medicare system so that the Autism/PDD item number can be used for FASD diagnosis, covering part of the cost of a Paediatrician, Psychologist, OT and Speech therapist
- Including FASD as a diagnostic category for support within school disability support schemes

Other research options mentioned during the group discussion were:

- A review of biological markers, such a rapid extension of knowledge, to enable a baseline.
- Genetics
- Epigenetics
- Bio-bank link to the register
- How might biomarkers influence response to treatments?
- How will epigenetics influence diagnosis and public health messages? Will it do this?
- A review of the literature for affect regulation in young children and infants – other conditions for guidance?

Future Research Ideas

Evidence-based screening tools and biomarkers for FASD

Exploring new diagnostic domains

Best practice for data sharing between portfolios

Early diagnosis for children without facial features

Advocacy Opportunities

Ensure widespread adoption of the Australian Guide to the Diagnosis of FASD and E-Learning Modules.

Facilitating access to funding for FASD diagnosis through use of MBS item numbers

The inclusion of the FASD impairments included in the NDIS funding model and school-based disability finding schemes



Therapy & Management Issues and Research Ideas

Economic Evaluations and Arguments

Present economic arguments for increasing support including health economists in policy/advocacy work

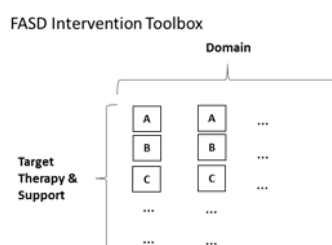
Ties into advocacy and funding:

- Who?
- Continuity over time and sectors
- Multiple agencies

Measuring changes in quality of life over the life course to understand impact on well-being

Models for Intervention and Toolbox of Strategies

- Model for what interventions might look like across the lifespan tools for impairment



- Reassess at various points and be open to creating a new plan
- Flexibility as & when needed to change toolbox choices
- Transfer of info to services throughout childhood holistic/connected approach
- Developmental approach, have options for support across the lifespan
- Include standard measure on quality-of-life for all OT specialists to use
- Consider again the categories for disability support and how these match to the domains of impairment to consider then that the right interventions, service and support are being provided by the NDIS
- Cross matching impairments from other areas of disability such as autism etc, and showing what is useful for that domain

Support for Case Workers

- Support for families currently inadequate
- Advocacy for additional support
- choosing support people (e.g. family/friends)
- Support workers for families they could help advocate for children and their families at schools
- Practical e.g. shopping, behavioural, school
- Support worker – evidence of effectiveness potentially needed for NDIS to fund
- Ability of people/families to access info (internet based not always assessable for all client groups)
- Outreach – family support
- Recommendations on how to access FASD key worker needed
- Key worker model exists in Canada

Employment

- What are the factors for success?
- Understanding strengths of people with FASD and linking to places of employment
- Provides social inclusion
- More evidence around what is working from carers (what factors supported the person staying in employment)
- Employment models – Curtin Autism employment trial
- What helps people with FASD to have success?



Therapy & Management Issues and Research Ideas cont.

Intersection of Trauma/FASD

- How different for a child/adult with both trauma and FASD in terms of need vs FASD + XYZ but no trauma
- How does trauma complicate the situation □ what needs to be in the “toolbox” for carers

Training

- Training on FASD required for various sectors, how training modules could be targeted for various sectors.
- How to respond on a practical level

Other research options mentioned during the group discussion were:

- More doctors, more diagnosis – faster access (NT, ACT & VIC has a lack of access)
- Outreach – clinicians going out to families to remove barriers to getting to clinics
- Birth mothers – guilt, denial – need awareness raising, removal of stigma
- Community ownership of this issue given our wide acceptance of alcohol use as a society. It becomes everyone’s responsibility to solve this problem and support families and children.
- A sensory/emotional regulation program for BHDC/Justice.
 - Literature review and scan of other programs
 - Could have Alert and/or other calming classroom theories (very hands-on and could include yoga, karate/jujitsu, running program, weights/strength training based on what the young persons strengths/interests are).
 - Incorporate goal setting, carry over into life post release, etc.
 - Work with staff to incorporate sensory strategies into the daily routine at BHDC.
 - Outcomes include executive function, emotional control, number of incidents at BHDC, recidivism rates etc.
- Identifying appropriate interventions to address multiple/complex impairments for the 10-18 yr old age group. One or more models are required to adjust for complex impairments

Future Research Ideas

Health economic study of FASD

Best practice service models for complex, multiple impairment across all ages

Understanding the positive factors for employment

Exploring the intersection of Trauma & FASD

Sensory/Emotional Regulation for youth in justice

The impact of additional support for families

Advocacy Opportunities

Additional support workers to manage complex cases and help families

Recommendations on how to access further support

Additional diagnosis clinics and clinicians trained in using Australia Guide

Campaign to remove birth mother stigma and increase community ownership