

# Queensland Child and Youth Clinical Network

## Fetal Alcohol Spectrum Disorders (FASD)

### Position Statement

This position statement has been prepared by the Queensland Child and Youth Clinical Network (QCYCN) following a request for information from the Preventative Health Unit regarding FASD services and resources. It is provided with the intent to facilitate health professionals and service planners to contextualise FASD broadly as a congenital health condition with lifelong sequelae. FASD is an umbrella term that encompasses all disabilities caused by prenatal exposure to alcohol. The health and developmental problems associated with this condition impact not only the affected individuals but their families and the community in general. This position statement emphasises the need for a multifaceted assessment and intervention approach encompassing a preventative health medical and developmental framework applicable to all Queensland communities. FASD is not a problem unique to indigenous communities.

1. Substance abuse during pregnancy can result in structural and neurological deficits in the foetus that have lifelong impacts on function including physical abilities, cognition, learning and behaviour, as well as on general health and wellbeing.
2. Alcohol is one of many substances (poisons / teratogens) that can result in damage to the unborn child if used during pregnancy. Others include some prescription medications and tobacco, marijuana, cocaine and other recreational drugs.
3. FASD is the most common non-genetic cause of intellectual impairment in the western world. More children are born each year with FASD than with autism, spina bifida, cerebral palsy and Down syndrome combined. Between 17 and 42 children are born in Australia each day with FASD, between 3 and 9 of these in Queensland. (Total births ABS 2013).
4. Prevalence
  - a. The best estimates are between 2-5% of the population
    - i. Australia wide 2% = 464,000. 5% = 1.14M
  - b. Although FASD is prevalent in all of Australia it has been identified as having a higher prevalence in the following populations
    - i. Children in the Juvenile Justice system
    - ii. Gaols
    - iii. Children in out of home care, statutory care and non-biological care
    - iv. Socially disadvantaged populations
5. No safe level of alcohol use in pregnancy has been identified. Therefore the most effective way to reduce the sequelae of exposure to alcohol and other substance use in pregnancy is by abstinence including through increasing public awareness of the effects of prenatal alcohol and drug exposure.
6. If prevention is not possible and an alcohol affected infant is born, then the families with the health, disability and education system need to manage the sequelae and meet the needs of these children and families. Families of these children may have many other prejudicial life factors to deal with that complicate support and intervention. The diagnosis itself of an alcohol related disorder in a child can be very stigmatising. In general diagnostic labels where appropriate should only be used after careful consultation with parents or care givers relating to the advantages and disadvantages of the label. Advantages may include access to service provision. Disadvantages include a lack of attention to a child's specific developmental profile, inclusive of strengths and weaknesses.

7. Alcohol use during pregnancy can result in the following:
  - a. Growth deficiency (low birth weight / failure to thrive)
  - b. Damage to the brain – encompassing a range from structural (including small head circumference – brain underdevelopment) to normal structure with functional deficits with cognition (intellectual impairment), learning difficulties (including attention, organising and planning – executive functions), and behavioural and mental health difficulties.
  - c. Birth defects
    - i. Heart defects
    - ii. Skeletal defects (scoliosis or curvature of the spine)
    - iii. Hearing loss
    - iv. Eye and vision abnormalities
    - v. Kidney abnormalities
  - d. Characteristic facial appearance
    - i. Thin upper lip
    - ii. Flattened area between upper lip and nose
    - iii. Short eye openings

Not all of these features will occur in the one child, therefore they all need to be considered and looked for when there is a history of heavy alcohol use in pregnancy.

8. FASD is significantly under-diagnosed in the Australia because:
  - a. FASD is perceived as a stigmatising diagnosis. Clinicians are reluctant to ask about prenatal alcohol exposure or to pursue potential diagnoses of FASD if positive.
  - b. The greatest burden of FASD lies within mainstream white middle class Australia where it remains undiagnosed or mislabelled. This is in part because 60% of pregnancies in Australia are unplanned and 63% of pregnancies are alcohol exposed.
  - c. FASD clinical expertise is rare and training is poor or non-existent. The majority of children with FASD (83%) are difficult to diagnose, because they do not have the identified facial features they are assumed to have normal brain function when in fact they have permanent diffuse brain injuries. A significant proportion of children do not have the classic physical features, but are impacted by nervous system changes that result in debilitating cognitive and behavioural deficits ranging in severity. Personnel required to support the diagnosis of FASD (child psychology, speech pathology & paediatricians) exist in government funded child development services in Queensland. However the full time equivalent and required discipline mix are inconsistently available.
9. A broad approach from the health system (from preventative measures to early identification, and intervention) is needed to meet the needs of these children and young people.
10. Core service areas include:
  - a. General Practitioners - In the absence of identifiable physical problems, presentation to GPs and community workers may often be the first part of detection.
  - b. General paediatric services
  - c. Paediatric subspecialty services as indicated (for example cardiology if there is a heart defect),
  - d. Child development services to help understand the developmental profile and the functional difficulties including with cognition and learning. Cross sector collaboration with disability services and education services is important.
  - e. Primary care services inclusive of child health services where early detection and developmental screening can occur.
  - f. Child and Youth Mental Health services – working with neurobehavioral issues
  - g. Private psychologists, social workers and behavioural specialists – on referral of GPs under GP Management Plan and/or Team care arrangements.
11. One perspective is that specific services are required for children with FASD. An alternate position is to support the enhancement of multidisciplinary child health and developmental services more broadly to ensure the needs of all children are met including those affected by alcohol and other drug use during

pregnancy, as well as promoting awareness of the importance of early detection and intervention for all developmental disorders and health conditions when identified.

12. Queensland child health nurses are trained in the use of developmental screening tools (Parent Evaluation of Developmental Status (PEDS)), and Ages and Stages Questionnaire tools (ASQ) on a statewide basis. This will assist in early detection of developmental difficulties inclusive of the developmental effects of Alcohol related disorders.
13. There are 10 multidisciplinary specialist child development services variably resourced across the state (Cairns, Townsville, Mackay, Rockhampton, Bundaberg – Harvey Bay, Sunshine Coast, Ipswich, Toowoomba, Gold Coast and Brisbane metro – LCCH) and one generalist paediatric service with a child development focus (South West HHS – Roma). All the specialist Child Development services are co-located with general paediatric services in our metropolitan and regional centres. The demand generally for child development services is high and wait lists are significant despite attention at a statewide level to service standards and practice improvement initiatives. Ideally a full complement of allied health professionals (psychologist, social worker, occupational therapist, speech pathologist and physiotherapist) are needed in a child development service to enable multidisciplinary assessment tailored to presenting functional difficulties, inclusive of when there is a question relating to FASD presentation and developmental profile. The full complement of these disciplines is missing from many of our Child Development Services.
14. There is no “specific treatment” for alcohol related disorders other than managing the functional and health sequelae. Research agendas aside these children are likely to be best managed in generalist services across the care continuum, with a collaborative approach. Augmentation of Child Development service resources as well as training will be of assistance, in the diagnosis and early intervention supports for this population of children and others with developmental impairments.
15. Health professionals require specific skills to contribute to an FASD diagnosis. There is a requirement for specific training relating to FASD and professional development regarding the assessment and management of developmental disability more broadly.

#### Authors:

**Dr. Alan Ruben**, M. Applied Epidemiology, FRACP FAFPHM  
Paediatrician and Public Health Physician  
Senior Staff Specialist, Torres and Cape Hospital and Health Service  
Community paediatrician, Apunipima Cape York Health Council

**Dr Doug Shelton**, MB BS, Dip Paed, FRACP.  
Clinical Director | Community Child Health  
Medical Director | Women's & Children's Health Services  
Gold Coast HHS

#### Tilda Rawal

Senior Occupational Therapist  
Child Development Service Outreach  
Cairns & Hinterland HHS

**Dr Kerri Webb**, MBBS, FRACP, GDPH  
Senior Staff Specialist Developmental –Behavioural Paediatrics Child Development Program  
Co-chair QLD Statewide Child & Youth Clinical Network  
Chair Child Development Subnetwork (CDSN) Qld Child and Youth Clinical Network  
Children's Health Queensland Hospital and Health Service

## References:

1. Fasdcenter.samhsagov
2. ABS Birth s 2013
3. Fitzpatrick, 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.
4. May PA et al. Prevalence and Characteristics of Fetal Alcohol Spectrum Disorders. *Pediatrics*. 2014 Oct 27;peds.2013–3319.