Response to Productivity Commission Draft report of Inquiry into Disability Care and Support

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Submission by:

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This is a personal submission made as an adjunct to the detailed response by the CDDHV. I have outlined my interest in the NDIS in an earlier individual submission.

In this response I wish to argue the case that both Foetal Alcohol Syndrome (FAS) and Foetal Alcohol Spectrum Disorder(FASD), an umbrella term to describe the range of disabilities and continuum of effects that may arise from prenatal alcohol exposure, should be accepted as conditions which can qualify an individual for receipt of Tier 3 funding and services.

I endorse the view put in the CDDHV submission that "diagnosis should not be an automatic key to the gateway to Tier 3 supports, but rather an assessment of core functional ability would underpin an understanding of the supports required" and I am not arguing that all people with these conditions should automatically qualify.

My concern is that this group of individuals, and especially those with FASD, which is not a formally recognised diagnosis, will miss out on the supports they need for their very real and lifelong functional disabilities, because the condition tends to be overlooked in our society and there is no strong lobby group advocating for these individuals.

Foetal Alcohol Syndrome (FAS) is the leading non-genetic cause of preventable intellectual impairment and the effects of this particular disability (FAS) on the child and family can be devastating and life-long. There is no established safe level of drinking during pregnancy and yet a Western Australian study found that nearly 60% of pregnant women continue to drink. Increased community awareness, political action and strong lobbying are clearly needed to improve prevention of this condition, and I have written to the Minister of Health and Ageing outlining my concerns.

My impression is that doctors probably don't enquire too stringently into a mother's drinking during pregnancy when a baby/child is not quite right, because if they did they might have to tell her that her drinking harmed her child. Even if a woman admits to having a few drinks early on and asks if this caused the problem, she is probably reassured. Also, because there is no cure for the damage done to the developing brain by alcohol, and currently in Australia, no specific supports, funding schemes or educational programs available to assist children with FAS and their families, paediatricians may feel there is nothing to be gained by giving such a grim label.

There is a tendency in the disability health and education fields to avoid giving children labels, especially where the prognosis is gloomy and there are few positive outcomes from having the label. I believe that making the diagnosis formally is very important for a number of reasons:

- The family and/or carers can learn about the condition and adjust their expectations to what is realistic, helping to avoid secondary impacts.
- The family/carers can seek out appropriate supports and services including support groups.
- Educators can understand, adapt and provide appropriate programs. While children with FAS /FASD are presenting at school without the diagnosis, there no reason for schools to try to provide programs suitable to their particular learning needs.
- Secondary relationship and educational impacts can be anticipated and ameliorated. Currently, children with undiagnosed FAS wreak havoc in schools and homes and communities throughout the land, picking up labels such as ADHD, Specific Learning Disability, Conduct Disorder, Oppositional Defiant Disorder, Juvenile Delinquent, Sociopathic Personality Disorder, and Repeat Offender along the way. Their underlying functional deficits are magnified and extended by the impact of their educational, social and relationship failures on their self esteem and the negative attitudes people develop towards them. Very toxic interactive cycles can occur.

Individuals and families dealing with other disabilities learn to accept and deal with the adverse social effects of labels. They form support and advocacy groups and strive to have the special needs of their particular group recognised and to have the stigma of the diagnosis reduced. Mental Health and Autism are cases in point. The label becomes even more readily accepted when the diagnosis opens doorways to specific funding and services.

The same could happen with FAS and FASD. A child cannot be blamed or despised for the behaviour of its mother during her pregnancy. A mother cannot be blamed or discriminated against if she was not made fully aware, before she became pregnant, that alcohol, even a small amount, can cause permanent damage to her child’s developing brain and have a life-long impact on the quality of both their lives. They are both victims of gross societal neglect and deserve all the support society can give them.

I have enclosed a draft copy of a Fact Sheet on Foetal Alcohol Syndrome that I am preparing for the CDDHV website and also an extract from the very comprehensive and research-based Wikipedia entry on FAS. The extract outlines the devastating secondary disabilities that occur in a large percentage of people with FAS/FASD and indicates some interesting and revealing protective factors that have been shown to reduce the incidence of secondary disabilities. I think this extract stongly reinforces the need for strong intervention at the highest levels into addressing this problem.

I think that if the NDIS were to acknowledge FAS and FASD as conditions which will lead to real consideration of an individual’s eligibility for Tier 3 supports, it could really help overcome the societal neglect of these devastating conditions.

Thank you for considering my submission.

Attachment 1

Foetal Alcohol Syndrome Fact Sheet (Final draft- June 2011)

The information in this CDDHV Fact Sheet has been adapted from Management Guidelines – Developmental Disability 2005, the FAS Community Resource Centre Website (www.fasstar.com/fas) , the NOFASARD website(www.nofasard.org) and Wikipedia(FAS and FASD entries), and also draws on the clinical experience CDDHV clinicians.

It covers both Foetal Alcohol Syndrome (FAS) and Foetal Alcohol Spectrum Disorder (FASD)

Introduction

Exposure of the developing foetal brain to alcohol can lead to brain injury and consequent developmental disability in some children. It is the leading preventable, non-genetic cause of intellectual disability in our community.

The foetal brain is most vulnerable in early pregnancy. A safe level of alcohol use during pregnancy has not been clearly identified but the risk of damage to the developing foetus increases with the level of alcohol ingestion.

The current NHMRC Guidelines on Alcohol Consumption recommend that for women who are pregnant or planning a pregnancy, not drinking is the safest option.

Several children in a family may be affected to varying degrees if maternal alcohol intake spans a number of pregnancies.

Foetal Alcohol Spectrum Disorder (FASD) is an umbrella term to describe the whole range of disabilities and continuum of effects that may arise from prenatal alcohol exposure. Some presentations may not meet all the criteria to be diagnosed as Foetal Alcohol Syndrome and the terms ‘partial FAS’, ‘foetal alcohol effects’, ‘alcohol-related neurodevelopmental disorders’ and ‘alcohol-related birth defects’ have been used to describe these cases.

How common is Foetal Alcohol Syndrome (FAS)?

In Australia the rate of Foetal Alcohol Syndrome is in the range of 0.02-2.6/1000 births.

The risk of Foetal Alcohol Syndrome varies greatly between genetic, racial and socio-economic groups and diagnosis rates in the indigenous community are in the upper range.

Foetal Alcohol Syndrome often goes unrecognized and undiagnosed and there can be reluctance amongst professionals to suggest to parents that alcohol is a possible cause of their child’s disability.

Foetal Alcohol Spectrum Disorder is even more likely to remain misdiagnosed or undiagnosed as the functional deficits it causes may not become apparent until later childhood or adolescence. Its true incidence in the community is uncertain.

Diagnosis and Prognosis

There is no specific test for FAS or FASD. Diagnosis depends on detecting patterns of abnormalities in growth, facial features and neurological dysfunction and in the context of a history of alcohol use in early pregnancy. Diagnosis of FAS can be difficult to establish as the characteristic facial features, if present, are not obvious and tend to become less obvious as the child grows older, and as there are few specialists in Australia trained and experienced in making the diagnosis.

In recognition of the disrupted life histories of many people with FAS/FASD, diagnosis can be made in the absence of a history of maternal alcohol intake during pregnancy, where there is no way to obtain that history retrospectively.

The neurological dysfunctions caused by the toxic effects of alcohol on developing brain cells are permanent and result in life-time disability. However, early diagnosis and appropriate interventions can make large differences in skill development and quality of the life for the person and family.

Lack of diagnosis or misdiagnosis can lead to inappropriate and ineffective interventions for behaviour management that contribute to the development of secondary disabilities.

Early diagnosis provides the opportunity of counselling the mother in relation to the risk that future alcohol intake poses for the development, health and well-being of future children.

Features of Foetal Alcohol Syndrome

Most people with FAS have the following characteristics:

1. Slow growth: The baby's height or weight is at or below the 10th percentile at any time, before or after birth. This growth delay may not persist and it can be difficult to obtain an accurate history of its presence when the diagnosis is being considered later in life.
2. Suggestive facial features: these include short or small palpebral fissues (eye openings), epicanthic folds, thin upper lip, flattened philtrum and maxillary hypoplasia. These features are most obvious between the ages of two and ten years old and may not be present at all if the mother did not drink during the time when the mid-face was developing (around day 20 of the pregnancy).
3. Central Nervous System (CNS) anomalies or dysfunctions: These characteristics may be the only features present in some individuals with Foetal Alcohol Spectrum Disorder (FASD) but they are the features which persist and cause life-long functional disability. They can include:
    a. microcephaly – head circumference at or below the 10th percentile;
    b. structural brain abnormalities - demonstrated on brain imaging;
    c. neurological damage – as evidenced by seizures, poor coordination, nystagmus and defects in hearing /vision;
    d. functional deficits – these become more apparent from the age of 4 years and can include:
        - global cognitive deficit (lower than expected IQ) or developmental delay
        - learning disabilities and poor information processing, despite normal IQ (poor problem solving skills, difficulty learning from consequences, difficulty with abstract concepts such as maths, time and money)
        - executive functioning deficits (lack of inhibition, poor planning and judgement)
        - motor function deficits (poor coordination, clumsiness, balance problems)

    - attention and hyperactivity problems (difficulty focusing and sustaining attention, poor impulse control)
    - problems with social skills (social perception and social communication problems, immaturity, inappropriate sexual behaviours and interactions)
    - other problems (not liking to be touched, memory deficits, language problems and inability to understand other people's perspectives)

It is important to recognise that these functional neurological deficits are symptoms of permanent, unchanging damage to the developing brain.

- They are not learned 'behaviour problems' and not within the person's control.
- They can result in adolescents and adults with FASD (including those with FAS) having difficulty achieving and maintaining independence due to problems with:
  - disruption of their education(up to 60% of those over 12 years old),
  - getting and keeping employment(up to 80% of those over 21 years old),
  - taking responsibility in routine household and daily living activities
  - taking responsibility for necessary paperwork (bills, benefit claims, etc), and
  - sustaining healthy relationships.
- They can lead to secondary disabilities such as:
  - mental illness (up to 90%),
  - forensic/legal problems (up to 60% of those over 12 years old),
  - alcohol or other substance abuse(up to 35% of those over 12 years old),
  - unwanted pregnancies,
  - vulnerability to sexual, emotional and physical abuse ,
  - risk-taking behaviours and self harm
  - accommodation other than the family home in childhood or adolescence(eg foster care, supported care, homelessness)

Management

Early formal diagnosis means that familymembers, carers, educators and other involved professionals can develop an understanding and acceptance of the nature of the child's learning and social difficulties and behaviours and can adjust their expectations and adopt management strategies and programs that are likely to be effective.

For example, many effective child-rearing strategies rely heavily on the child's ability to learn from natural or logical consequences (if you do/don't do this, this consequence will/won't follow). For a child with severely impaired capacity to learn from consequences, this approach will lead to repeated deprivation for the child and increasing frustration for the adult. Different strategies need to be developed if progress towards learning social rules, and other skills, is to be made.

However well-targeted educational, behavioural, social and support programs may assist in the prevention of the secondary effects and enable the child to capitalise on their strengths. With appropriate support, interventions and guidance they can grow into loving, affectionate, friendly, caring, loyal people with a range of talents and a determination to succeed in life. Health management will require a focus on prevention and on mental health, advocacy, social support, and service coordination for individuals and families concerned. Early psychiatric referral is required if there is a change in behaviour that could suggest the onset of a mental illness.

Families (and substitute families) also require on-going support and advocacy in their role as primary carers for someone with FASD.

Prevention

Alcohol use and abuse in individuals and in communities is related to many factors including:

- **Individual factors**: self esteem, physical and psychological pain and distress, sense of belonging and being valued, sense of hope and optimism, personal financial and social circumstances, individual beliefs and values;
- **Family factors**: family beliefs and values, socio-economic situation and opportunities, cultural expectations and norms, mental and physical health;
- **Community factors**: peer and community expectations and behavioural norms.
- **Cultural factors**: cultural practices, beliefs, expectations and values, hope and opportunity; and
- **Social factors**: socio-economic factors, vocational and recreational opportunities, support and service provision, mental and physical health services.

Addressing the issues of alcohol use and abuse includes attention to the associated social, economic, cultural and health issues.

It is very important for health and welfare professionals to discuss alcohol use with any woman who is pregnant or planning pregnancy and to inform her of the risk to the foetus of maternal alcohol intake.

School and public education programs need to reinforce that the message that no alcohol is the safest choice during pregnancy as research has not established a safe amount or a safe time during the pregnancy. The risk of permanent damage to the developing baby increases with increased alcohol intake, and especially with binge drinking, but even small amounts can cause brain damage at crucial stages of foetal development

For more information on FAS and FASD see:

National Organisation for Fetal Alcohol Syndrome And Related Disorders (NOFASARD)
www.nofasard.org
FAS Community Resource Centre Website (www.fasstar.com/fas)
Management Guidelines – Developmental Disability 2005

Attachment 2

Extract from Wikipedia entry on FAS

Secondary disabilities

The secondary disabilities of FAS are those that arise later in life secondary to CNS damage. These disabilities often emerge over time due to a mismatch between the primary disabilities and environmental expectations; secondary disabilities can be ameliorated with early interventions and appropriate supportive services.[10]

Six main secondary disabilities were identified in a University of Washington research study of 473 subjects diagnosed with FAS, PFAS (partial fetal alcohol syndrome), and ARND (alcohol-related neurodevelopmental disorder):[6][10]

- Mental health problems — Diagnosed with ADHD, Clinical Depression, or other mental illness, experienced by over 90% of the subjects
- Disrupted school experience — Suspended or expelled from school or dropped out of school, experienced by 60% of the subjects (age 12 and older)
- Trouble with the law — Charged or convicted with a crime, experienced by 60% of the subjects (age 12 and older)
- Confinement — For inpatient psychiatric care, inpatient chemical dependency care, or incarcerated for a crime, experienced by about 50% of the subjects (age 12 and older)
- Inappropriate sexual behavior — Sexual advances, sexual touching, or promiscuity, experienced by about 50% of the subjects (age 12 and older)
- Alcohol and drug problems — Abuse or dependency, experienced by 35% of the subjects (age 12 and older)

Two additional secondary disabilities exist for adult patients:[6][10]

- Dependent living — Group home, living with family or friends, or some sort of assisted living, experienced by 80% of the subjects (age 21 and older)
- Problems with employment — Required ongoing job training or coaching, could not keep a job, unemployed, experienced by 80% of the subjects (age 21 and older)

Protective factors and strengths

Eight factors were identified in the same study as universal protective factors that reduced the incidence rate of the secondary disabilities:[6][10]

- Living in a stable and nurturant home for over 72% of life
- Being diagnosed with FAS before age six
- Never having experienced violence
- Remaining in each living situation for at least 2.8 years

- Experiencing a "good quality home" (meeting 10 or more defined qualities) from age 8 to 12 years old
- Having been found eligible for developmental disability (DD) services
- Having basic needs met for at least 13% of life
- Having a diagnosis of FAS (rather than another FASD condition)