



**House of Representatives Standing Committee on
Social Policy and Legal Affairs**

Inquiry into Foetal Alcohol Spectrum Disorder

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The National Council on Intellectual Disability (NCID) was established over 50 years ago by parents and friends, in an endeavour to improve the quality of life of people with intellectual disability and to fill the need for national unity and information.

The Council is the recognised national peak body with the single focus on intellectual disability, ie, our actions and priorities centre on issues that affect the lives of people with intellectual disability and their families. Our mission is to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members.

NCID has over 5,000 members representing all 8 States and Territories. In addition to having people with disability on its Board, NCID receives policy advice from Our Voice. Our Voice is a committee the membership of which is exclusively people with intellectual disability representing all States and Territories.

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Statement of Principles

- ☼ All people have inherent dignity and worth and equal and inalienable rights.
- ☼ All people are valued members of the Australian Community.
- ☼ People with intellectual disability as equal participating members of the Australian Community have the same rights:
 - ☼ to respect for their individual autonomy and independence
 - ☼ to make their own choices
 - ☼ to participate in decisions which affect their lives
 - ☼ to pursue any grievance which affects their lives
 - ☼ to diversity of choice for housing, education, work, recreation and leisure
 - ☼ to equity and justice
 - ☼ to be empowered to take their full place in the Australian Community
 - ☼ to dignity and privacy in all aspects of their lives

National Council on Intellectual Disability will:

- ✓ work to make the Australian Community one in which people with intellectual disability have full and equal enjoyment of all human rights and fundamental freedoms and are involved and accepted as equal participating members.
- ✓ promote and protect the human rights of all persons with intellectual disability, including those who require more intensive support.

Consultation Statement

National Council on Intellectual Disability consults people with intellectual disability and family members through our State and Territory Agency Members. In particular we:

- ➡ conduct an annual survey of members and stakeholders
- ➡ hold two meetings a year, rotating through all States and Territories
- ➡ present at the Having a Say Conference each year, attended by over a 1,000 delegates the majority of whom have a disability
- ➡ hold forums on specific issues
- ➡ sponsor actions and representations on issues of importance to people with disability

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The National Council on Intellectual Disability Submission

House of Representatives Standing Committee on Social Policy and Legal Affairs

Inquiry into Foetal Alcohol Spectrum Disorder

Introduction

The National Council on Intellectual Disability (NCID) welcomes and supports this long overdue inquiry into Foetal Alcohol Spectrum Disorder (FASD). NCID supports and endorses NOFASARD as the leading National Peak Body on FASD.

NCID has a very particular interest in addressing this issue as:

Prenatal alcohol exposure, and the resulting FASD, is recognized as the commonest preventable cause of intellectual disability. (K.D.O'Malley, 2007)

It is of great concern to NCID that people with FASD are the single largest most undiagnosed, unrecognised cause of disability in the community which attracts no funding and no support or assistance. NCID is strongly supportive of NOFASARD's statement that the abysmal failure of Australian Governments to address FASD is a clear breach of human rights particularly the UN Convention on Rights of Persons with Disabilities:

States Parties shall: provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children.
(UNCRPD Article 25 (b))

Prevention Strategies:

Community Awareness

"None for Nine"

NCID strongly endorses the need for a national awareness advertising campaign to be developed that clearly articulates the very real danger of causing brain damage to unborn babies by drinking alcohol during pregnancy.

The "one punch can kill" style of advertising which includes people telling how drinking alcohol during pregnancy has affected the development of their child and their family life can be very powerful. There is also a very great need to increase awareness through advertising to young people the dangers of binge drinking and pregnancy.

In conjunction with national advertising there is an urgent need to develop a national curriculum module for high school students that accurately demonstrates the dangers of drinking alcohol

whilst pregnant. Young people need to grow up from a young age knowing and understanding that alcohol is a neurotoxin and teratogen and what the consequences are for developing fetuses.

NCID calls on the Australian Government to immediately institute a mandated health warning label system.

Any labelling needs to carry visually clear messages which are unambiguous and clearly state the health hazards associated with alcohol consumption particularly during pregnancy. (See NCID's Submission to COAG Review of Food Labelling Law and Policy 2011; ncid.org.au/submissions)

Health Promotion and Prevention

NCID supports the recommendations for prevention strategies as developed by the WA Government in their proposed FASD *Model of Care*, particularly with relation to the involvement of health professionals in identifying and supporting women at risk. NCID recommends that National Guidelines be developed and implemented in all States and Territories in the following areas:

- Improving access to antenatal and maternity services for disadvantaged groups
- Provision of information to all pregnant women and their families about substance use and the risks associated with alcohol use during pregnancy including abstinence
- Establishment of protocols for the use of brief interventions addressing maternal alcohol use during pregnancy
- Increasing the collaboration between GPs, maternity and newborn service providers and alcohol and other drug services to ensure comprehensive drug and alcohol maternity services for all pregnant women, including in rural and remote areas
- Screening for and managing, alcohol withdrawal for pregnant women
- Referral of pregnant and post-partum women with alcohol-related dependency to comprehensive health services addressing parenting and child and family wellbeing
- Implementation of opportunistic screening for alcohol consumption for all women of child-bearing age and the use of brief interventions where indicated
- Implementation of universal screening in pregnancy (first antenatal visit and each trimester) and the use of brief interventions where indicated
- Development of a national dataset on alcohol use during pregnancy.

(*Summary List of Recommendations* Department of Health, Western Australia. Fetal Alcohol Spectrum Disorder Model of Care. Perth: Health Networks Branch, Department of Health, Western Australia; 2010.)

Intervention Needs

Diagnosis

NCID calls for the **Australian Government to immediately finalise the development and implement the use of a National Diagnostic tool for FASD for use by the medical profession and other health providers.**

The following excerpt from the report "*Education of Students with Foetal Alcohol Spectrum Disorder K Crawford 2008*" sums up the imperatives for early diagnosis

Early diagnosis is a protective factor associated with fewer secondary disabilities (Streissguth et al., 1996).

- *Diagnosis assists families and the person with FASD to understand their behaviours in terms of neurological damage, and not that they are wilfully misbehaving.*

- *A diagnosis helps parents and caregivers set realistic and appropriate expectations for their child.*
- *Diagnosis can be a dual diagnosis of child and birth mother. The birth mother may be able to receive counselling from this point.*
- *Diagnosis of one child may mean successful intervention with the mother to prevent the birth of another child with FASD.*

As recommended by the WA Government all at risk newborns and children identified as at risk should be referred for further screening and assessment for FASD.

NCID supports the recommendation that screening for FASD be incorporated into the Medicare funded Child Health Checks and all Aboriginal Child and Maternal Health Programs.

Comprehensive training for GPs and other health professionals in understanding and diagnosis of FASD is urgently required to be undertaken.

Without a diagnosis whole generations of children are being left without the opportunity to access the range of supports and services they need to address their difficulties and achieve their full potential.

NCID calls upon the Australian Government to immediately recognise Foetal Alcohol Spectrum Disorder as a registered disability and as a condition eligible for support from health, education, employment and community services.

[Developmental Support](#)

NCID calls on the Australian Government to immediately move to include children and families living with FASD in the next round of the “Better Start Initiative”.

In this way families will be able to get appropriate services and interventions for their child from an early age.

Work needs to commence on appropriate early intervention strategies for implementation across health and education. It is imperative that a partnership is developed between “professionals”, parents and carers in the development and implementation of strategies.

A great deal can be learnt from overseas experiences particularly in Canada and the UK where extensive work has already been undertaken in developing programs and referral pathways for children diagnosed with FASD.

NCID calls upon the Australian Government to initiate a joint working party to develop appropriate protocols and national guidelines for early intervention. Such a working party must include adequate and appropriate representation from NOFASARD and organisations representing people with a disability.

[Management Issues](#)

NCID calls upon the Australian Government to ensure all people with FASD are included in and covered by the 2010 – 2020 National Disability Strategy.

All people diagnosed with FASD are likely to have significant difficulties with learning in a range of areas, particularly mathematics, time and handling money, understanding of concepts, consequences, retrieving and storing information, following instructions, executive functioning and

short term memory. Frequently, also associated can be behavioural issues and difficulties with social skills often with related impulsivity and distractibility, attention deficit and hyperactivity. All this is highly likely to affect the person's basic living skills and ability to function well in society. In addition there are a range of possible physical health problems that can be associated with FASD.

It is imperative that in order that people with FASD are able to reach their full potential, function fully in society and not become yet another statistic in the justice and community services systems, that they are provided with appropriate and adequate support and services in the areas of rights protection, economic security, learning and skills development, health and well being and personal and community support.

Education

Currently, without any formal recognition of Foetal Alcohol Spectrum Disorder as a disability there is no specific support offered to students within the education system. Many students suffer greatly at school due to their significant learning difficulties and are frequently stigmatised as "difficult", "obstructive", "defiant" and "wilful". It is estimated that of the proportion of children at school with FASD at least 35% will have an intellectual disability.

"Because of our lower rate of diagnosis in Australia it is highly likely we have many students with FASD currently in our schools. Awareness of FASD is only just emerging in Australia. Education, along with areas such as health, welfare, disability, justice does not have a well developed understanding of FASD and its impact on individuals, families and their communities. Existing policies, structures and strategies across government and non government sectors do not yet recognise FASD and are therefore not as supportive of the FASD population as they could be."

Education of Students with Foetal Alcohol Spectrum Disorder K Crawford 2008

There needs to be far greater awareness developed amongst educators and education departments regarding the needs of children with FASD.

By comparison, students with an Autism Spectrum Disorder and those with Acquired Brain Injury also have significant deficits in their neurological functioning and benefit greatly from government and community awareness, knowledge, funding and positive strategic initiatives.

NCID calls upon the Australian Minister for Education to work with all State and Territory counterparts to ensure all teachers and teachers' aids receive appropriate training and education in recognising and understanding the needs of children with FASD in order to better support children with FASD throughout their school life.

The Australian Government needs to work with Education departments, universities and experts in developing and adopting education standards and appropriate teaching tools and manuals to support children with FASD in reaching educational expectations.

As Kym Crawford shows in her Report the use of best practise for teaching students with FASD is vitally important if they are to succeed at school. *"Success at school is the starting point for success as an adult."*

Ensuring all children with FASD receive prompt and appropriate early intervention and schooling that meets and addresses their needs in order to learn and meet their full potential will prevent many children from being lost to society in the future through secondary disabilities or difficulties such as emotional and societal problems, Mental health problems, disrupted school experiences, trouble with the law, confinement, inappropriate sexual behaviour and alcohol and drug problems.

The potential cost to society both financially and socially of not supporting these children and ensuring they receive adequate and appropriate support through the school system is enormous.

Justice System

There is growing evidence that a considerable proportion of people in prison with an intellectual disability may in fact have FASD:

Current research indicates that a disproportionately large number of youth and adults with FASD are engaged with the legal system...

The complex learning and behavioural difficulties observed in people with FASD increase their risk of undertaking or being guided into criminal behaviour.

(Doing Time - Time for Doing, Indigenous youth in the criminal justice system, House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs June 2011)

NCID calls upon the Australian Government to work with the State and Territory Justice Departments in developing appropriate guidelines for supporting people with FASD in the justice system and preventing them from entering the justice system particularly Juvenile Justice.

This proportion of the prison population frequently have no access to support or services and often remain in prison for longer than their term due to an inability to provide them with appropriate support in the community.

NCID would refer the Committee to the work being done by the Aboriginal Disability Justice Campaign.

Employment

Insufficient data prevents us from knowing how many people with FASD are not being engaged in the workforce to their full capacity. However, it would be appropriate to estimate that given the range and extent of people with FASD's disabilities it is likely they would find it very difficult to access employment without support and assistance.

NCID calls upon the Australian Government to ensure all Disability Employment Agencies provide adequate and appropriate training and education to their staff in understanding the disabilities and difficulties associated with FASD and how to best support and assist people with FASD to access meaningful employment.

Summary of Recommendations

NCID makes the following recommendations to the Committee on Social Policy and Legal Affairs *Inquiry into Foetal Alcohol Spectrum Disorder*:

That:

- **The Australian Government immediately finalise the development and implement the use of, a National Diagnostic tool for FASD for use by the medical profession and other health providers;**
- **screening for FASD be incorporated into the Medicare funded Child Health Checks and all Aboriginal Child and Maternal Health Programs;**

- **The Australian Government immediately recognises Foetal Alcohol Spectrum Disorder as a registered disability and as a condition eligible for support from health, education, employment and community services;**
- **The Australian Government to initiates a joint working party to develop appropriate protocols and national guidelines for early intervention. Such a working party must include adequate and appropriate representation from NOFASARD and organisations representing people with a disability;**
- **The Australian Government to ensure all people with FASD are included in and covered by the *2010 – 2020 National Disability Strategy*;**
- **The Australian Minister for Education works with all State and Territory counterparts to ensure all teachers and teachers aids receive appropriate training and education in recognising and understanding the needs of children with FASD in order to better support children with FASD throughout their school life;**
- **The Australian Government works with Education departments, universities and experts in developing and adopting education standards and appropriate teaching tools and manuals to support children with FASD in reaching educational expectations;**
- **The Australian Government works with the State and Territory Justice Departments in developing appropriate guidelines for supporting people with FASD in the justice system and preventing them from entering the justice system particularly Juvenile Justice;**
- **The Australian Government ensures all Disability Employment Agencies provide adequate and appropriate training and education to their staff in understanding the disabilities and difficulties associated with FASD and how to best support and assist people with FASD to access meaningful employment.**

The National Council on Intellectual Disability welcomes this enquiry and would be delighted to make ourselves available to present to the Inquiry.