

Management needs

- 5.1 Individuals with Fetal Alcohol Spectrum Disorders (FASD) have a range of special needs and require a variety of sometimes intensive support for the duration of their lifetime.
- 5.2 This chapter addresses the lack of data on the prevalence of FASD in Australia. This data is important for a number of reasons, including devising and targeting management strategies appropriately, adequately resourcing areas of high prevalence, measuring the potential economic and social cost of FASD, and confirming the need for improved FASD awareness and funding.
- 5.3 As discussed in the previous chapter, health treatment and intervention for people with FASD and support for their carers can be difficult to access even when armed with a professional diagnosis. Similarly, appropriate management strategies in other areas are not readily available, in part due to the limited knowledge of FASD prevalence.
- 5.4 Professor Elizabeth Elliott cautioned that:

There is no point making a diagnosis and then leaving people in the lurch. We have to have follow-up – follow-up with families coping with the grief of a diagnosis, follow-up in the schools, follow-up in the justice system and follow-up in the health system.¹
- 5.5 This chapter considers the common experiences of children and young adults with FASD in relation to care, education and the criminal justice system, and the lack of follow-up in these domains. The chapter outlines the challenges in each of these areas and considers actions that have been

1 Professor E Elliott, Professor of Paediatrics and Child Health, University of Sydney, *Committee Hansard*, Mimbi, 11 July 2012, p. 9.

identified through the inquiry. The primary obstacles to improving management of FASD appear to be a lack of public information and understanding of FASD, reinforced by the fact that FASD is not currently recognised by the Commonwealth Government as a disability.

Lack of prevalence data to inform management

5.6 As discussed in Chapter 2, the prevalence of FASD in Australia is not well-documented. Prevalence data is an essential foundation for developing and implementing management strategies.

5.7 Dr Lisa Studdert stated that:

... to get a handle on [FASD] and be able to craft our responses, both prevention and management, we do need to have good data on what the current prevalence is and the trends over time – are we seeing an increase in this problem or is it stable? – and then on the overall situation in terms of the quantity of the problem.²

5.8 However, the Department of Health and Ageing (DoHA) stated that there are deficits in the knowledge and research base:

We still do not know enough about the factors which contribute to FASD, its prevalence or what the most effective models of early intervention are to reduce its secondary impact on mental health, education and social dysfunction.³

5.9 This was supported by health experts. Dr Jane Latimer and Dr Colleen O’Leary pointed out that prevalence studies conducted so far primarily investigate Fetal Alcohol Syndrome (FAS) only, leaving a data gap on other conditions on the FASD spectrum where FAS facial features are not present.⁴

5.10 However, it is difficult to measure prevalence without consistent screening and diagnostic practices. As discussed in the previous chapter, Australia is lagging behind in national screening and diagnostic practices. Yet the Australian National Preventive Health Agency argues that:

Before accurate prevalence rates of FASD can be estimated in Australia, routine assessment and recording of maternal alcohol

2 Dr L Studdert, Manager, Australian National Preventative Health Agency (ANPHA), *Committee Hansard*, Canberra, 15 March 2012, p. 3.

3 D Butt, Deputy Secretary, Commonwealth Government Department of Health and Ageing (DoHA), *Committee Hansard*, Canberra, 28 June 2012, p. 2.

4 Dr J Latimer, Senior Research Fellow, Lililwan Project Chief Investigator, *Committee Hansard*, Canberra, 24 November 2011, p. 5; Dr C O’Leary, *Submission 92*, p. 2.

use during pregnancy, education about diagnosis of FASD, and methods for collecting national data would need to be established.⁵

- 5.11 The result is a vicious circle where collecting prevalence data is hindered by the lack of routine, nation-wide assessments of maternal alcohol consumption and uniform diagnosis of FASD, which in turn are more difficult to implement without good data on the extent of FASD. The Telethon Institute for Child Health Research (Telethon Institute) stated that 'without diagnostic data, it is difficult to define the prevalence [of FASD] and therefore lobby for health training in this area'.⁶
- 5.12 The Anyinginyi Health Aboriginal Corporation argued that:
- This lack of concrete evidence has contributed to the neglect of FASD and Australia's failure to address its issues despite clear knowledge of its existence dating back decades.⁷
- 5.13 The Committee heard evidence from some contemporary prevalence studies that will contribute to national data on FASD. The Lililwan Project measured the prevalence of FASD in 45 communities in the Kimberley region of Western Australia⁸ and last year a study commenced into the prevalence of FASD among children up to 12 years of age in Perth.⁹ DoHA advised that the Australian Institute of Health and Welfare undertook a scoping study on best-practice methods of collection and reporting FASD prevalence data.¹⁰
- 5.14 Quality prevalence data is 'vital to being able to better determine the extent of FASD in Australia and develop programs to support people with FASD'.¹¹

Carers

- 5.15 Caring for children with FASD is all-consuming and difficult, and early intervention strategies can be expensive. Carers of people with FASD need financial support in the same way that other carers of people with

5 ANPHA, *Submission 45*, p. 3.

6 Telethon Institute for Child Health Research (Telethon Institute), *Submission 23*, p. 2.

7 Anyinginyi Aboriginal Health Service, *Submission 3*, p. 2.

8 Professor E Elliott, University of Sydney, *Committee Hansard*, Canberra, 24 November 2012, p. 1.

9 Foundation for Alcohol Research and Education/Public Health Association of Australia (FARE/PHAA), *Submission 36*, p. 18.

10 DoHA, *Submission 78*, p. 3.

11 FARE/PHAA, *Submission 36*, p. 17.

disabilities are supported in recognition of their limited income-earning capacity due to caring responsibilities.

- 5.16 Children with FASD require intensive care and supervision, as described earlier, and can often be in need of a high level of health service coordination. Sue Miers explained that:

In order to reach any kind of sustained function, successful strategies often involve adapting the environment to prevent inappropriate behaviour from occurring in the first place. This is really hard work. It usually requires constant total supervision, highly structured and significantly altered physical environments and time-consuming interventions.¹²

- 5.17 This places great stress on carers, who may be unaware of the needs of children with FASD or unable to manage the severe behavioural problems. Without adequate information or resources, carers struggle to access the necessary intervention strategies.

- 5.18 The National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) advised the Committee that they receive many queries from parents and carers and support workers seeking assistance for children who they suspect of having FASD. For example, Sue Miers said:

I am a Family Counsellor and Support Worker and am seeing more children which I suspect have effects of alcohol and I am often at a loss as to where to send them or the help I can give. Parents/carers and guardians appear to be quite frustrated that the level of recognition and support is just not available.¹³

- 5.19 A large number of carers raising children with FASD are foster carers or grandparents and other kin, rather than biological parents. It is not uncommon for women with FASD to consume alcohol during their own pregnancy.

- 5.20 Prue Walker informed the Committee that there is strong international evidence that children with FASD are over-represented in the child protection system, and that prenatal alcohol exposure greatly increases the risk of children entering care, including foster care, residential care, or family placements.¹⁴

12 S Miers, Chair, National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD), *Committee Hansard*, Melbourne, 22 June 2012, p. 19.

13 NOFASARD, *Submission 46*, Attachment A, p. 2.

14 P Walker, *Submission 29*, p. 4.

- 5.21 The two main factors which have an influence on whether children with FASD might enter the care system are:
- Abuse and neglect due to parental alcohol use; and
 - Risks to growth and development, including failure to thrive.¹⁵
- 5.22 The Telethon Institute told the Committee that American and Canadian research has found 75 per cent of children in foster care come from family histories of mental illness or drug and alcohol abuse. These children are often a higher risk group for FASD.¹⁶
- 5.23 NOFASARD reported that a South Australian study found that parental drug or alcohol misuse was associated with 70 per cent of the children who entered out of home care for the first time in 2006 (in 40 per cent of cases, mothers were the users). This study also claims that parental drug and alcohol misuse is the driving factor for children entering into care.¹⁷
- 5.24 Prue Walker made the important point that intervention by the child protection system for behavioural problems is more likely to focus on addressing parenting issues, obtaining behavioural support through the school system, and working with parents or carers to manage the child's behaviour rather than considering FASD.¹⁸ However, an understanding of organic brain damage is necessary for people to realise that the behaviour of individuals with FASD is about what they 'cannot do' rather than 'will not do'.¹⁹
- 5.25 Barbara Smith told the Committee that:
- None of the children who I believe suffer from FASD have had an easy life and their problems are getting worse in adulthood. None have reached the potential we would hope for our children, despite very committed and caring foster homes.²⁰
- 5.26 Prue Walker stated that there needs to be more research into the experience of children with FASD who are in out of home care. She outlined some of the difficulties for children with FASD who come to the attention of the child protection system:
- FASD is more complex to diagnose when facial features are not present;
 - Focus may be on keeping the family healthy and safe;

15 P Walker, *Submission 29*, p. 4.

16 H Jones, Manager, FASD Projects, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 25.

17 NOFASARD, *Submission 46*, p. 11.

18 P Walker, *Submission 29*, p. 8.

19 A Foale, *Submission 24*, p. 2.

20 B Smith, *Submission 4*, p. 2.

- Child protection workers may not be able to predict that the child may also experience speech and language problems or other developmental delays due to lack of resources or information;
- It may take some time before the carer can identify that the child is not meeting developmental milestones and be slow to get on waiting lists to visit health professionals; and

5.27 There could be other possible explanations for behaviour problems, learning difficulties or developmental delays.²¹

Figure 5.1 The impact of FASD on children in care

Typically, children with FASD require:

- Stable, safe environments
- Structure and routine
- Repetition and predictability
- Consistency
- Reward and redirection rather than punishment
- Close supervision
- Role modelling

Children in care can experience changes and instability which are particularly difficult for children with FASD to process. These include:

- Repeated attempts at reunification with birth or extended family
- Access with family which may be planned or unplanned
- Placement breakdown
- Multiple placements prior to long term placements being identified
- Changes in childcare or school depending on placement

These children already have a background of abuse or neglect which impacts on their ability to cope with change. For Indigenous children in the Northern Territory in particular, these changes and transitions can be very challenging. Moving between family of origin, kinship care and foster care involves changes in culture, language and location. All of these are a challenge for a child with FASD to manage.

Source Ms Prue Walker, *Submission 29*, p. 8.

5.28 NOFASARD is concerned about the problems of children transitioning to independence from the care system at the age of 18. They state that maturation is delayed for children and young people with FASD and if

21 P Walker, *Submission 29*, pp. 8-9.

they leave state care systems without lifelong supports in place, they could experience repeated crises on their own.²²

- 5.29 Prue Walker stated that it is likely that young people with FASD who do not receive adequate support and management in care will become adults who continue to rely on social services through life, even when they achieve a level of success.²³ Many will become involved in the criminal justice system.

Challenges

- 5.30 Unfortunately, the out of home care system in Australia is already stretched beyond capacity. One foster carer believes that FASD has 'affected the foster care system itself which is currently in crisis with the numbers of difficult children who need placement'.²⁴
- 5.31 The Committee heard from a number of committed foster organisations and carers who are struggling to get information on FASD or financial support to provide the intensive therapies that are required to manage developmental and learning delays.
- 5.32 Raymond Metzger and his wife are fostering five children with FASD, but were not given any indication from the child protection department that these children might have FASD-related issues.²⁵ He stated that once the children had been diagnosed by a paediatrician, they were not eligible for any carers' funding as the children were not regarded as having special needs.²⁶
- 5.33 Another foster couple could not get respite care for their son who was diagnosed with FAS:

Both government and non-government agencies, and individual professionals all abdicated responsibility for him over and over again, saying that 'he did not meet their criteria'. Apparently he did not meet anyone's criteria, because no one was required to acknowledge FASD as a legitimate disability. He, and by association the whole family, became a hot potato in nearly every context.²⁷

22 NOFASARD, *Submission 46*, p. 11.

23 P Walker, *Submission 29*, p. 9.

24 B Smith, *Submission 4*, p. 2.

25 R Metzger, *Committee Hansard*, Cairns, 31 January 2012, p. 30.

26 R Metzger, *Committee Hansard*, Cairns, 31 January 2012, p. 31.

27 Name withheld, *Submission 8*, p. 1.

- 5.34 Barnardos described the difficulties of aligning FASD with the current eligibility criteria for support services:

One of the unexpected difficulties that I came across is that, even though I have a nearly three-year-old who has quite a clear diagnosis of FAS, they are unable to actually access [NSW Family and Community Services] funded services because there is no global developmental delay or a delay in at least two areas. ... When you are looking at a very uncertain future of what to expect in terms of her needs much later in life, the carers will have to look at funding speech therapy, occupational therapy and other different therapy services because they cannot access them through the public system.²⁸

- 5.35 The Australian Children's Commissioners and Guardians (ACCG) stated that support for families caring for children with FASD is essential so that families are able to provide appropriate support to affected children.²⁹ Carers and parents particularly need FASD information, extra support, guidance and respite.³⁰

Figure 5.2 National Organisation for Fetal Alcohol Syndrome and Related Disorders

Established in 1999, the National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) is an independent and charitable national organisation working to prevent fetal alcohol exposure and support those living with an FASD and those who support them. NOFASARD is a registered Health Promotion Charity and the national peak community organisation representing the interests of parents, carers and others interested in or affected by FASD.

NOFASARD provides resource and reference information; education and training; online information and electronic resources; and support, advocacy and referral options for parents/caregivers and families supporting children/adolescents and adults who have been diagnosed with an FASD or are assessed as being at risk.

'The stress on family relationships in particular cannot be understated. NOFASARD receives many inquiries from family members struggling to care for children/adolescents and adults with FASD because professional service providers do not recognise or understand the disability nor do they respect parent/carer efforts to describe FASD. Parents/carers/families are often

28 B Hijniakoff, Case Manager, Barnardos, *Committee Hansard*, Sydney, 13 April 2012, p. 30.

29 Australian Children's Commissioners and Guardians (ACCG), *Submission 62*, p. 7.

30 NOFASARD, *Submission 46*, p. 11.

overwhelmed if not physically and emotionally exhausted from dealing with challenging behaviours that arise from this brain based disability. Too often, professional assessment assumes the behaviours to be an individual's choice; the product of a dysfunctional family; poor parenting practices; or other environmental factors.'

Source: <http://www.nofasard.org.au/> and Submission 46, p. 8.

5.36 The Commonwealth Government provides support payments that may be available to individuals with FASD and their carers. For the carers of eligible individuals with a disability, two support mechanisms are relevant:

- the Carer Payment and
- the Carer Allowance.

5.37 The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) explained that:

Carers of people with FASD may ... be eligible for financial assistance through the carer allowance or carer payment, and some carers may be entitled to receive child disability assistance payment, available to carers of a child with a disability under 16 years who attract the payment of carer allowance for their carer... We will continue to provide financial support such as carer payments, carer allowance and the disability support pension in cases where people with FASD have significant functional impairments or high care needs.³¹

5.38 The Carer Payment is an income and assets tested income support payment available to people who, because of the demands of their caring role, are unable to support themselves through substantial paid employment.³² The payment can be made to carers of children (up to the age of 16) and adults.

5.39 The Carer Payment is available to carers who care for a child with an 'intense' rating against the Disability Care Load Assessment (Child) Determination and a medical certificate indicating that six or more months of personal care is required.³³ The Disability Care Load Assessment (Child) Determination takes into account two behavioural domains, functional abilities, and special care needs. Thus a person caring for

31 C Edwards, Group Manager, Strategic Priorities and Land Group, Commonwealth Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA), *Committee Hansard*, Canberra, 28 June 2012, p. 3.

32 FaHCSIA, *Submission 8*, Answer to Question on notice, p.1.

33 Ashurst Australia, *Submission 49*, p. 17.

someone with FASD could receive this payment if they fulfil the level of care required.³⁴

- 5.40 For carers of adults, the Carer Payment is assessed not on the level of care needs but on a type of disability, that is 'a physical, intellectual or psychiatric disability' assessed against the Adult Disability Assessment Tool.³⁵ This does not include a cognitive disability. Accordingly, carers of adults with FASD who do not have any of the above recognised forms of disability are not eligible, even though they may have received the Carer Payment previously when the care recipient was under 16, due to the level of care required.³⁶
- 5.41 The Carer Allowance is a supplementary payment for carers who provide daily care and attention in a private home for people with a disability who need significant care and attention.³⁷ The Carer Allowance is not subject to income or means testing.
- 5.42 To receive the Carer Allowance when caring for a child, the carer must care for a child who is a 'disabled child'. This child must either have a disability on the List of Recognised Disabilities or be given a qualifying rating of 'intense' under the Disability Care Load Assessment (Child) Determination.³⁸ When caring for an adult, the Carer Allowance is available when caring for a 'disabled adult', which is defined in the same way as for the Carer Payment.³⁹ Thus, carers of adults with FASD who do not have a physical, intellectual or psychiatric disability would not be able to receive the Carer Allowance.
- 5.43 Individuals with FASD may be able to access some Commonwealth Government disability support payments themselves once they turn 16, to assist with their housing and care needs. These are:
- the Disability Support Pension;
 - the Youth Disability Supplement; and
 - the Mobility Allowance.
- 5.44 The Disability Support Pension is available to individuals aged 16 years or over with a 'physical, intellectual or psychiatric impairment'. This impairment must be severe, registering 20 points or more under the

34 L Corver, Acting Branch Manager, Disability and Carers Payment Policy Branch, Disability and Carers Group, FaHCSIA, *Committee Hansard*, 28 June 2012, p. 10.

35 Ashurst Australia, *Submission 49*, p. 18.

36 Ashurst Australia, *Submission 49*, p. 18.

37 FaHCSIA, *Submission 8*, Answer to Question on notice, p.1.

38 Ashurst Australia, *Submission 49*, p. 19.

39 Ashurst Australia, *Submission 49*, p. 19.

- Impairment Tables. The person must be unable to work or participate in the supported wage system.⁴⁰
- 5.45 Disability Support Pensioners can receive the Youth Disability Supplement if they are younger than 21 and can only work up to 30 hours per week.⁴¹
- 5.46 To receive the Mobility Allowance, a person must be aged over 16, have a physical or mental disability, and be unable to use public transport without substantial assistance either permanently or for an extended period due to this disability. They must also be undertaking employment, vocational training, a vocational rehabilitation program or voluntary work, or seeking work.⁴²
- 5.47 As discussed in earlier, people with FASD can have serious cognitive impairments that require intensive care and supervision, but may not have physical disabilities, low IQ, or psychiatric or mental illness. These people would then be ineligible for these disability support payments. For example, the Committee heard about a young woman with FASD whose IQ is just above the threshold of 70 for intellectual disability:
- Her IQ is 74 and she just falls outside disability support and yet at 16 she still has to be reminded how to wash, clean her teeth and dress appropriately.⁴³
- 5.48 The Commonwealth Government provides a variety of other support for people with disabilities. These include:
- the Australian Disability Parking Scheme;⁴⁴
 - community care services;⁴⁵
 - the National Companion Card;⁴⁶
 - the National Disability Advocacy Program;⁴⁷
 - Outside School Hours Care for Teenagers with Disability;⁴⁸
 - Special Disability Trusts;⁴⁹
 - Australian Disability Enterprises;⁵⁰

40 Ashurst Australia, *Submission 49*, p. 14.

41 Ashurst Australia, *Submission 49*, p. 16.

42 Ashurst Australia, *Submission 49*, p. 20.

43 Name withheld, *Submission 50*, p. 1.

44 FaHCSIA, *Australian Disability Parking Scheme*.

45 DoHA, *Help to stay at home - community care*.

46 Australian Government, *The National Companion Card Scheme*.

47 FaHCSIA, *National Disability Advocacy Program*.

48 FaHCSIA, *Outside School Hours Care for Teenagers with Disability*.

49 FaHCSIA, *Special Disability Trusts*.

- Disability Employment Services;⁵¹
 - CRS Australia (formerly known as the Commonwealth Rehabilitation Service);⁵²
 - the Disabled Australian Apprentice Wage Support Program;⁵³
 - Job in Jeopardy Assistance;⁵⁴ and
 - Job Access.⁵⁵
- 5.49 Eligibility for these services often hinges on having a diagnosed 'disability', which is undefined.⁵⁶ Ashurst Australia analysed the eligibility criteria for these services, and found that most would be available to some people with FASD if their condition was severe, but that there was no guarantee or clarity on determining eligibility.⁵⁷

Actions

- 5.50 Currently access to the above support payments is unpredictable and unclear for individuals with FASD and their carers. The eligibility criteria and terminology need to be changed to include cognitive impairment to ensure access for all people with FASD. As the payment system does not include a specific code for FASD, FaHCSIA is unaware how many people with FASD or their carers receive income support.⁵⁸
- 5.51 FaHCSIA explained that even though FASD is not on the List of Recognised Disabilities:
- ... people can still test their eligibility for carer allowance under the disability care load assessment, which is something that measures the level of care required by the child and the level of

50 Australian Government, *Australian Disability Enterprises*.

51 Commonwealth Government Department of Education, Employment and Workplace Relations (DEEWR), *Disability Employment Services*.

52 Australian Government, *CRS Australia*.

53 Commonwealth Government Department of Human Services, *Disabled Australian Apprentice Wage Support*.

54 Commonwealth Government Department of Human Services, *Job in Jeopardy Assistance*.

55 Australian Government, *Job Access*, <<http://jobaccess.gov.au/Home/Home.aspx>> viewed 9 July 2012.

56 See for example, FaHCSIA, <<http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/outside-school-hours-care-for-teenagers-with-disability>>; DEEWR, *Support for Job Seekers – Overview*, <<http://www.deewr.gov.au/Employment/Programs/DES/SJS/Pages/home.aspx>>; Commonwealth Government Department of Human Services, *Disabled Australian Apprentice Wage Support*, <<http://www.humanservices.gov.au/customer/services/centrelink/disabled-australian-apprentice-wage-support>> viewed 10 July 2012.

57 Ashurst Australia, *Submission 49*, pp. 26–39.

58 L Corver, FaHCSIA, *Committee Hansard*, 28 June 2012, p. 9.

care provided by the carer – or, in the case of carer allowance adult, using the adult disability assessment tool which measures the functional ability of the care receiver. So the carers of people with fetal alcohol spectrum disorder who are severely affected would qualify.⁵⁹

5.52 Ashurst Australia pointed out that this method is ‘more time consuming and difficult’ than the streamlined process of identifying a disability on the List of Recognised Disabilities.⁶⁰

5.53 Moreover, Ashurst Australia emphasised that ‘impairment’ is not defined in legislation, and considers that:

The adoption of a broader and clearer term than ‘intellectual impairment’ would create greater certainty for people with FASD and other cognitive impairments about whether or not they fall within this limb of the test for a Disability Support Pension.⁶¹

5.54 Ashurst Australia prefers the term ‘cognitive impairment’ as it is more inclusive:

Cognitive impairment encompasses, but is not limited to, intellectual impairment, and is not measured by reference to IQ. ... a cognitive impairment or disorder means a loss of brain function affecting judgment and resulting in a decreased ability to process, learn or remember information.⁶²

5.55 Including FASD on the List of Recognised Disabilities and defining disability to include cognitive impairment would enhance access for people with FASD to the Carer Allowance for children, Carer Payment for adults, the Disability Support Pension and other disability support payments.

5.56 Some witnesses recommended that FASD should be included in the Commonwealth Government’s Better Start for Children with a Disability Initiative (Better Start).⁶³ Better Start provides funding for early intervention services and treatments for children diagnosed with Down syndrome, cerebral palsy, Fragile X syndrome, or a moderate or greater vision or hearing impairment, including deafblindness, and from 2013, Prader Willi, Williams, Angelman, Kabuki Make Up, Smith-Magenis,

59 L Corver, FaHCSIA, *Committee Hansard*, 28 June 2012, p. 8.

60 Ashurst Australia, *Submission 49*, p. 19.

61 Ashurst Australia, *Submission 49*, p. 15.

62 Ashurst Australia, *Submission 49*, p. 9.

63 See National Rural Health Association, *Submission 40*; National Council on Intellectual Disability (NCID), *Submission 9*; NOFASARD, *Submission 46*; Russell Family Fetal Alcohol Disorders Association (RFFADA), *Submission 1*; FARE/PHAA, *Submission 36*.

CHARGE, Cornelia de Lange or Cri du Chat syndromes or microcephaly.⁶⁴ Additional funds are available for children who live in rural or remote locations.

- 5.57 The Foundation for Alcohol Research and Education and Public Health Association of Australia noted that as currently relatively few children are diagnosed with FASD, the cost of expanding Better Start to include FASD would not be prohibitive, whereas the benefit would be enormous.⁶⁵ Ms Russell stated that people with FASD and their carers need a funding initiative for early intervention for FASD similar to Better Start.⁶⁶

Figure 5.3 Helping children with autism

The Australian Government has committed ongoing funding to address the need for services for children with Autism Spectrum Disorder, their families and carers.

The package includes:

- Autism Advisors who provide information regarding eligibility, available funding and Early Intervention and other support services.
- Funding for early intervention services to facilitate improved cognitive, emotional and social development prior to a child starting school.
- PlayConnect Playgroups, providing play-based learning opportunities.
- Early Days family workshops, aimed at equipping parents and carers to more effectively manage the pressures they face in raising their children at home.
- A website that provides information, online resources and interactive functions to support parents, families, carers and professionals.
- An additional one-off payment for families who reside in outer regional or remote areas who have difficulty accessing early intervention services.

Source <http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/helping-children-with-autism>

- 5.58 The Commonwealth Government already funds Helping Children with Autism, an Autism Spectrum Disorder-specific early intervention package that is similar to Better Start. See Figure 5.3 above for information on Helping Children with Autism initiative.

64 FaHCSIA, *Better Start for Children with Disability Initiative*, <<http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/better-start-for-children-with-disability-initiative>> viewed 7 November 2012.

65 FARE/PHAA, *Submission 36*, p. 5.

66 A Russell, Executive Officer, RFFADA, *Committee Hansard*, Cairns, 31 January 2012, p. 3.

- 5.59 There may be more hope for support for people with FASD when the National Disability Insurance Scheme (NDIS) is implemented after its planned roll-out next year. DoHA and FaHCSIA stated that the NDIS:
- ... will ensure that people with significant and permanent disability receive the care and support they need over their lifetimes, regardless of where they live or how they acquired their disability.⁶⁷
- 5.60 The Australian Human Rights Commission is very supportive of the NDIS, claiming that it:
- ... has the potential to transform the way services are funded and delivered, ensuring people with significant and ongoing disability, which would include many people with FASD, are better supported and have greater choice and control. The NDIS will also mean better support for the families and carers of people with disability.⁶⁸

Education

- 5.61 Children with FASD typically have learning and behavioural disabilities that manifest or become more apparent in the classroom context. Just like any other child with a disability, children with FASD should receive the support necessary to function and progress in school. In a similar way to disability income support, schools struggle to access resources and funds to provide the extra supports for children with FASD as it is not currently a recognised disability.
- 5.62 Children with FASD may have difficulty with the stimulating, demanding and complicated environment of school.⁶⁹ They may need a different education model:
- It is not right to keep them struggling in the classroom which they find hard and often boring. We need to have a curriculum for life, rather than an academic curriculum, to suit these kids.⁷⁰

67 DoHA/FaHCSIA, *Submission 78*, p. 5.

68 Australian Human Rights Commission, *Submission 54*, p. 11.

69 Manitoba Government Canada, *What Early Childhood Educators need to know about Fetal Alcohol Spectrum Disorder (FASD)*, p. 8, <http://www.gov.mb.ca/healthychild/fasd/fasdearly_en.pdf> viewed 11 September 2012.

70 Professor E Elliott, University of Sydney, *Committee Hansard*, Canberra, 24 November 2012, p. 2.

Figure 5.4 Performance problems associated with FASD

Prenatal alcohol exposure often results in central nervous system dysfunction that affects a student's ability to successfully perform in an academic setting. The frequency and magnitude of these problems varies greatly among affected students and is not correlated to IQ scores.

- Compromised executive functioning; may have difficulty planning, predicting, organizing, prioritizing, sequencing, initiating, and following through. Difficulty setting goals, complying with contractual expectations, being on time, or adhering to a schedule.
- Difficulty with memory; information input, integration, forming associations, retrieval, and output. Difficulty learning from past experiences. Often repeats the same mistake over and over again in spite of increasingly severe punishment.
- Inconsistent memory or performance; may remember on Monday but forget by Thursday.
- Difficulty with abstract concepts such as time, math, or money.
- Impaired judgment; often unable to make decisions. Difficulty differentiating safety from danger, friend from stranger, or fantasy from reality.
- Inability to generalize information; difficulty forming links and associations, unable to apply a learned rule in new setting.
- Communication challenges; appears to understand instructions, but actually does not comprehend. Often repeats rules verbatim, then fails to apply them.
- Language problems; difficulty comprehending the meaning of language and accurately answering questions. May agree or confabulate, comply or fill in the blanks. May talk excessively, yet be unable to engage in a meaningful exchange. The sheer volume of words may create the impression of competence.
- Slow cognitive pace; may think more slowly, may require minutes to generate an answer rather than seconds. Students with FASD are 'ten-second people in a one-second world.'
- Slow auditory pace; central auditory delays means language is processed more slowly, requiring more time to comprehend. Many students only grasp every third word of normally paced speech.
- Perseveration; may be rigid, get stuck, have difficulty switching gears, stopping an activity, or transitioning to a new one. Often reacts strongly to changes in setting, program, and/or personnel.
- Dysmaturity; often functions socially, emotionally, and cognitively at a much younger level of development than chronological age.
- Impulsivity coupled with inability to abstract and predict outcomes; acts first and then is able to see the problem after the fact.

Source: Adapted from D Malbin, 'Fetal Alcohol Spectrum Disorder and the Role of Family Court Judges in Improving Outcomes for Children and Families', *Juvenile and Family Court Journal*, Spring 2004, p. 9.

- 5.63 The Australian Special Education Principals' Association noted that FASD is identified as the largest cause of non-genetic learning disabilities.⁷¹ Moreover, the National Council on Intellectual Disability (NCID) stated that at least 35 per cent of children at school with FASD have an intellectual disability.⁷²
- 5.64 Children with FASD may have a cognitive rather than intellectual impairment or low IQ, but nonetheless have difficulties with numeracy, literacy, memory, attention, and judgement.⁷³ Other symptoms, such as speech, hearing or vision problems, behavioural issues, hyperactivity, short attention span and difficulties forming social relationships, contribute to the high risk of children with FASD not completing school.⁷⁴
- 5.65 When the source of behavioural and social problems is not recognised, children with FASD are considered to be uncontrollable or troublesome. The NCID stated that children with FASD were often branded as difficult, obstructive, defiant and wilful.⁷⁵
- 5.66 Students with FASD are often suspended or removed from schools due to their behaviour. At a FAS workshop in Cape York, Queensland, a participant noted that some local children that had been expelled from school were not to blame as they had symptoms of FAS.⁷⁶ One foster carer said that her child was removed from the mainstream school system at the age of seven due to his failings at school.⁷⁷ Another carer is home-schooling her child:
- ... due to an expulsion for violent and threatening behaviour and we do not know how long this situation will last because there are no positions available in the foreseeable future in a school that is able to cope with his needs.⁷⁸

Challenges

- 5.67 Such situations can occur when there is insufficient knowledge and understanding of FASD or resourcing of support. Many parents and carers

71 F Forbes, 'Towards Inclusion: An Australian Perspective', *Support for Learning*, vol. 22, no. 2, 2007, p. 67.

72 NCID, *Submission 9*, p. 8.

73 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 5; NOFASARD, *Submission 46*, p. 3.

74 Alcohol and other Drugs Council of Australia (ADCA), *Submission 33*, p. 4.

75 NCID, *Submission 9*, p. 8.

76 L Hayes, *Submission 80*, p. 19.

77 Name withheld, *Submission 8*, p. 2.

78 T Harth, Foster Carer, Barnardos, *Committee Hansard*, Sydney, 13 April 2012, p. 32.

were placed in the position of having to educate schools on FASD, with varying degrees of success.

- 5.68 In one situation the parents had provided information to the school and the teacher about FASD and their child, but the teacher continued to view FASD-related behavioural issues as naughtiness:

Even though we had given her all the information and done all that sort of stuff, she still thought it was a behaviour issue – which drives me crazy.⁷⁹

- 5.69 In contrast, another teacher was keen to learn all she could about FASD after receiving an educational DVD from the foster carer:

She asked if I minded if she kept [the DVD] at school to let the other teachers see it because there would be other children who may have the same behaviours, which may come under the same diagnosis.⁸⁰

- 5.70 In his submission, Paul Harper compared and contrasted the schools that his foster daughter attended. Some were not willing to listen to and work with parents or carers, whereas others were cooperative and proactive:

Ashwood School performed wonderfully in teaching Debbie to read and do everyday tasks like tie her laces. The energy and attitude in tailoring programs that actually work was obvious to see. They kept us on our toes, introducing new things on their own initiative and involving us in every aspect of curriculum development. They always had multiple staff at meetings and always resolved issues by following them up promptly. This developed over 5 years into a truly collaborative approach to Debbie's learning.⁸¹

- 5.71 The Commonwealth Disability Standards for Education 2005 clarify the obligations of education and training providers to ensure that students with disabilities are able to access and participate in education and training on the same basis as those without disability.⁸²

- 5.72 However, a recent review of these standards noted that the effectiveness of the Standards is somewhat compromised by a lack of resources, such as funding allocations, professional development for educators and the provision of support services.⁸³ Another concern was the lack of

79 L Chataway, *Committee Hansard*, Townsville, 31 January 2012, p. 17.

80 D O'Leary, Foster Carer, Wee Care Shared Family Care, *Committee Hansard*, Townsville, 31 January 2012, p. 7.

81 P Harper, *Submission 14*, p. 7.

82 DEEWR, *Disability Standards for Education*, 2005.

83 DEEWR, *Report on the Review of Disability Standards for Education 2005*, 2012, p. 48.

transparency about funding decisions and how funds for students with disability were allocated in the school setting. It was suggested that the consultation process would be improved if parents were advised of how funding decisions were determined.⁸⁴

- 5.73 The Committee heard evidence that supported these findings. In Fitzroy Crossing, the Committee heard that the funding structure of the Department of Education does not permit the employment of Allied Health professionals.
- 5.74 Barnardos claimed that they have been asked by schools that lacked sufficient funding to provide teachers' aides to enable their foster children to attend class.⁸⁵
- 5.75 Despite advice from the Queensland Government that students should receive assistance based on their needs rather than their diagnosis, Robert Chataway's foster son was initially denied assistance under the Education Adjustment Program as he did not fit into the six categories of disability and would therefore not attract 'a bucket of funds'.⁸⁶
- 5.76 Another foster carer in South Australia contacted NOFASARD out of concern at the lack of funding from the Department of Education and Child Services for FAS 'as it seems that no one knows what it really is'.⁸⁷
- 5.77 The Committee heard from schools and teachers who are committed to ensuring the best education for students with FASD but who lack funding and resources to accomplish this. Dale Vaughan, a School Health Nurse in Broome, stated that:
- ... one of the biggest issues we have in the school system is that there is no funding for these children. ... there is no funding under the Schools Plus system to assist the teachers with these children, who have very significant needs and are very difficult to teach.⁸⁸
- 5.78 In Fitzroy Valley, the Lililwan Project has resulted in a number of children being diagnosed with FASD and provided with management plans. Although the management plans should result in appropriate strategies, including educational strategies, for the children:
- ... what we find now is that the workload for teachers and for administrators in the school is going up exponentially in terms of the recommendations that are being made in these reports to help

84 DEEWR, *Report on the Review of Disability Standards for Education 2005*, 2012, p. 48.

85 E Cox, Senior Manager, Barnardos Australia, *Committee Hansard*, Sydney, 13 April 2012, p. 30.

86 Dr R Chataway, *Committee Hansard*, Townsville, 31 January 2012, pp. 14-15.

87 NOFASARD Disorders, *Submission 46b*, p. 1.

88 D Vaughan, School Health Nurse, Broome Community Health, *Committee Hansard*, Broome, 12 July, p. 1.

us provide the support for these kids but not having the resources to do it effectively.⁸⁹

Actions

- 5.79 The principal of Fitzroy Valley District High School informed the Committee what the Australian Government needed to do:

From a schooling perspective, what the government can do is to start by recognising that [FASD] is a disability. We cannot do anything while it is just words and is not supported. Obviously the state system provides the support staff to work with the kids, but they will not recognise it if the federal government does not recognise it as a disability.⁹⁰

- 5.80 According to the Department of Education, Employment and Workplace Relations, the Commonwealth Government has committed extra funding for schools to provide the support that students with a disability require:

The *More Support for Students with Disability* initiative will provide \$200 million in additional funding over two years to government and non-government education authorities to support their work with students with disability and/or learning difficulties. ...

Education authorities will be able to use funding to increase support for students with disability by building the capacity of schools and teachers to better meet their individual needs. This will be accomplished through selection of a range of activities that may include the provision of coordinated services by health specialists within a school (e.g. occupational therapy), adapted curriculum tailored to students' needs based on the latest expert advice and provision of assistive technology to support students' learning in the classroom.⁹¹

- 5.81 Such funding is essential for teachers to be able to work in tandem with allied health professionals:

The availability of health professionals such as psychologists in the education system would reduce the stress to students with FASD and other students. The role of these health professionals would be to support teachers on how to manage children with FASD. This

89 B Wagner, Teacher, Fitzroy Valley District High School, *Committee Hansard*, Mimbi, 11 July, p. 10.

90 D Bridge, Principal, Fitzroy Valley District High School, *Committee Hansard*, Mimbi, 11 July, pp. 2-3.

91 DEEWR, *Submission 55a*, p. 3.

- would enable capacity building within the education system on the management of children and young people with FASD.⁹²
- 5.82 In addition to funding, educating teachers about FASD and how to teach students with FASD is crucial. The Telethon Institute noted that education and support for teachers 'is important to enable them to understand the different approaches required to aid a child with a FASD through school'.⁹³
- 5.83 Wendy Takle, who is a foster carer, agreed and recommended 'more resources and more education for the teachers on how to actually teach the children' as each child with FASD may have different learning abilities and needs.⁹⁴
- 5.84 The ACCG submitted that:
- ... educational resources that support the learning of children with FASD are urgently required. Maintaining engagement with the educational system is an important protective factor in children's lives and has significant bearing on their life outcomes.⁹⁵
- 5.85 The NCID called upon the Commonwealth Government to work with states and territories to improve FASD training for teachers and teachers' aides.⁹⁶
- 5.86 There are some information sources on FASD for teachers and education providers in Australia. These resources have been developed by a range of organisations and are available online.
- 5.87 The *Count Us In!* teaching resource package from Western Australia outlines the disability requirements that must be met in schools and provides information on a variety of disabilities, including FASD.⁹⁷ The Office for Disability in Victoria provides similar information on disabilities, including FASD, for schools through the Bar None Community Awareness Kit.⁹⁸
- 5.88 *Physical as anything.com* is a website on medical conditions, written for teachers, schools, healthcare professionals, students and families and endorsed by the New South Wales Department of Education and

92 Australian College of Children and Young People's Nurses, *Submission 63*, p. 2.

93 Telethon Institute, *Submission 23*, p. 4.

94 W Takle, Foster carer, Barnardos, *Committee Hansard*, Sydney, 13 April 2012, p. 34.

95 ACCG, *Submission 62*, p. 7.

96 NCID, *Submission 9*, p. 8.

97 Disability Service Commission WA, *Count Us In! Teacher Information: Book 1*, 2005.

98 Office for Disabilities, *Bar None Community Awareness Kit for Schools*, <www.officefordisability.vic.gov.au> viewed 18 September 2012.

- Communities and NSW Health.⁹⁹ It includes a detailed description of FASD and its educational implications, written by experts in the field of FASD.
- 5.89 However, none of these resources compare to those available to teachers in Canada. The province of Manitoba has issued a comprehensive document titled *What Educators Need to Know about Fetal Alcohol Spectrum Disorder (FASD)*.¹⁰⁰ This booklet provides detailed information on the needs of children with FASD at school and appropriate teaching strategies. A companion document, *What Early Childhood Educators Need to Know about Fetal Alcohol Spectrum Disorder (FASD)*, is also available.¹⁰¹
- 5.90 Alberta has published a textbook, *Teaching students with Fetal Alcohol Spectrum disorder: Building strengths, creating hope*, in its special needs series of education resources.¹⁰²

Criminal Justice System

- 5.91 Individuals with FASD who come into contact with the criminal justice system may not have their disabilities taken into account by judicial officers. Due to the broad spectrum of FASD, some people with FASD may fit within current definitions of disability for the purpose of sentencing that takes into account reduced culpability. Others, however, may not, despite having significant impairments that should be considered mitigating factors.
- 5.92 In the *Doing Time – Time for Doing* report, the Standing Committee on Aboriginal and Torres Strait Islander Affairs highlighted the connection between FASD and the involvement of young people with the criminal justice system in Australia.¹⁰³

99 NSW Department of Education and Communities, <www.physicalasanything.com.au> viewed 18 September 2012.

100 Healthy Child Manitoba, *What Educators Need to Know about Fetal Alcohol Spectrum Disorder (FASD)*, 2010 <<http://www.gov.mb.ca/healthychild/fasd/resources.html>> viewed 11 September 2012.

101 Healthy Child Manitoba, *What Early Childhood Educators Need to Know about Fetal Alcohol Spectrum Disorder (FASD)*, 2010, <<http://www.gov.mb.ca/healthychild/fasd/resources.html>> viewed 11 September 2012.

102 Alberta Learning, Special Programs Branch, *Teaching students with Fetal Alcohol Spectrum disorder: Building strengths, creating hope*, 2010, <www.learning.gov.ab.ca/k_12/specialneeds/resource.asp> viewed 5 November 2012.

103 Parliament of Australia, Standing Committee on Aboriginal and Torres Strait Islander Affairs, *Doing Time – Time for Doing: Indigenous youth in the criminal justice system*, June 2011, pp. 96-103.

- 5.93 International research shows that there is a high prevalence of youth and adults with FASD in the criminal justice system. The Alcohol and Other Drug Council of Australia (ADCA) cited statistics from the National Organization on Fetal Alcohol Syndrome in the US, which stated that 61 per cent of adolescents and 58 per cent of adults with FASD in the US have been in trouble with the law, and that 35 per cent of those with FASD over the age of 12 had been incarcerated at some point in their lives.¹⁰⁴ Another US study found that 60 per cent of people with FASD have been in contact with the criminal justice system.¹⁰⁵
- 5.94 Anecdotal evidence suggests that people with FASD are over-represented in the Australian legal system as well, but the lack of diagnostic and prevalence numbers mean that currently the problem is difficult to quantify.¹⁰⁶
- 5.95 The First Peoples Disability Network (FPDN) stated that:
- Our evidence is anecdotal but in the experience of the FPDN it is not uncommon to meet Aboriginal people who are either in jail or are in contact with the criminal justice system who it would appear have some form of FASD ... The FPDN is not aware of any quantitative data on the prevalence of FASD amongst the Aboriginal prison population for instance which may serve to highlight the significance of FASD as an issue.¹⁰⁷

Challenges

- 5.96 Legal Aid NSW stated that the behaviours that are symptomatic of FASD are what bring people with FASD to the attention of the criminal justice system.¹⁰⁸ Individuals with FASD tend to behave impulsively, which 'may lead to stealing things for immediate consumption or use, unplanned offending and offending behaviour precipitated by fright or noise'.¹⁰⁹ ADCA added that people with FASD:
- ... are typically impulsive and have trouble foreseeing the consequences of their actions; they may have a poor sense of

104 ADCA, *Submission 33*, p. 8.

105 H Douglas et al, 'Judicial Views of Foetal Alcohol Spectrum Disorder in Queensland's Criminal Justice System', *Journal of Judicial Administration*, vol. 21, no. 3, February 2012, p. 178.

106 Dr B Towler, Principal Medical Advisor, DoHA, *Committee Hansard*, Canberra, 28 June 2012, p. 8; National Drug Research Institute, *Submission 20*, p. 5; FARE/PHAA, *Submission 36*, p. 22.

107 First Peoples Disability Network, *Submission 75*, p. 5.

108 D Maher, Solicitor in Charge, Children's Legal Service, Legal Aid New South Wales, *Committee Hansard*, Sydney, 13 April 2012, p. 17.

109 H Douglas, 'The Sentencing Response to Defendants with Foetal Alcohol Spectrum Disorder', *Criminal Law Journal*, vol. 34, 2010, p. 223.

personal boundaries; many are very susceptible to peer pressure, they can be easily led, and their judgment is often poor.¹¹⁰

- 5.97 A Canadian judge noted that ‘governments now know people with FASD will increasingly fill the prisons because they have a high rate of re-offending, act on impulse and do not consider the consequences’.¹¹¹
- 5.98 Lack of appropriate health, education or welfare support services can lead to individuals with FASD being diverted to, rather than away from, the criminal justice system. A joint submission from NSW and ACT legal services advised that they have noticed that behavioural problems associated with disabilities are being addressed by schools, care workers and parents with apprehended violence orders instead of referral to relevant health and welfare organisations. This is particularly the case for people with FASD as it is not a registered disability and therefore not linked to any specific support services.¹¹²
- 5.99 Such situations are particularly acute in remote areas where support services are non-existent, leading to the criminal justice system acting as the first point of contact for people with behavioural problems stemming from disabilities.¹¹³ The ADJC expressed their general concern about what they describe as the widespread and unwarranted use of prisons for the management of unconvicted Indigenous people with cognitive impairments.¹¹⁴
- 5.100 Although people with FASD are more likely to come into contact with the criminal justice system, the system is not designed for people with the type of impairments associated with FASD. Individuals with FASD may confess or agree to any statement due to high suggestibility and eagerness to please.¹¹⁵ Moreover, they may have little understanding of the various legal processes and the gravity of their situation.¹¹⁶

110 ADCA, *Submission 33*, p. 8.

111 H Douglas, ‘The Sentencing Response to Defendants with Foetal Alcohol Spectrum Disorder’, *Criminal Law Journal*, vol. 34, 2010, p. 228.

112 Legal Aid New South Wales and Aboriginal Legal Service (New South Wales/Australian Capital Territory), *Submission 44*, p. 4.

113 P McGee, Coordinator, Aboriginal Disability Justice Campaign (ADJC), *Committee Hansard*, Sydney, 13 April 2012, p. 25.

114 ADJC, *Submission 43*, p. 1.

115 H Douglas et al, ‘Judicial Views of Foetal Alcohol Spectrum Disorder in Queensland’s Criminal Justice System’, *Journal of Judicial Administration*, vol. 21, no. 3, February 2012, p. 180.

116 Western Australia Department of the Attorney-General, *Equality Before the Law Bench Book*, 2009, p. 4.2.7 <www.supremecourt.wa.gov.au/_files/equality_before_the_law_bench_book.pdf> viewed 5 November 2012.

- 5.101 Ian McKinley, a member of the Aboriginal Disability Justice Campaign described the tragic pathway from cradle to prison of many children with FASD:

Most of these children are born in remote communities to mothers who are alcoholics. They have no parental care. They fail to thrive. They are in and out of the local clinics. They end up in hospital with gastro and other ailments from the early infant years. Their care usually defaults to aunts or grandmothers on a community. By that stage they are on Territory child welfare, or state child welfare in the other states. They go through to early schooling. They drop out of school. It is probably misdiagnosed as attention deficit syndrome. They are teased and rejected by the other children in the community. Their challenging behaviours are starting to manifest by that stage. By the age of six or seven, they start to become victims of physical abuse and sexual abuse, especially the young females. They have no peer inclusion. They are still under child welfare at that stage. By the early teen years, they have probably been referred to the Territory's aged and disability services, but no services are offered at all... Then they start to fall within the reach of the criminal justice system. At the age of 18, they come under adult guardianship. There are still no services offered, so virtually they are coming off the communities to prison as the first intervention of any significance, and that is where they remain. And they are either under this unfitness-to-plead legislation on indefinite prison based custodial supervision orders or they are in and out of jail as recidivists, virtually full-time prisoners. The recidivists perhaps represent the greater number than those on custodial supervision orders – and there is simply no proposed solution.¹¹⁷

- 5.102 Individuals with FASD also have difficulty understanding consequences and connecting cause and effect. As such, responding to orders, sentences or rehabilitation is often unsuccessful:

As a result of deficits in executive function resulting in memory difficulties, inability to plan and failure to recognise the consequences of actions, many of those with FASD are likely to fail to pay fines and to breach probation orders and good behaviour bonds.¹¹⁸

117 I McKinley, Member, ADJC, *Committee Hansard*, Sydney, 13 April 2012, p. 18.

118 H Douglas, 'The Sentencing Response to Defendants with Foetal Alcohol Spectrum Disorder', *Criminal Law Journal*, vol. 34, 2010, p. 228.

5.103 Dr David Hartman agreed:

Because of the nature of their disability they are not very good at learning from experience and do not respond very well to normal juvenile justice measures like a community service order or a good behaviour order or something of that nature, which requires a bit of ability to plan and learn from experience.¹¹⁹

5.104 However, identifying individuals with FASD is not straightforward:

People with brain impairments often act like everyone else. They learn what is called a 'cloak of competency.' They walk and talk and act completely normal. They mimic the behaviours of others and learn coping strategies to hide their struggles.¹²⁰

5.105 In addition to disproportionately frequent interactions with the criminal justice system, submitters were concerned that people with FASD are not receiving justice or appropriate treatment in the courts. This is primarily due to limited understanding and diagnosis of FASD, and the specific terminology used in the law:

As with welfare-related law and policy, the terms used to determine who may have their disability taken into account in the criminal law, and the definitions of those terms, are varied and often inconsistent.¹²¹

5.106 Ashurst Australia, a law firm that has been providing pro bono legal services for people with mental illness or cognitive impairment, made a comprehensive submission to the inquiry on how criminal law affects individuals with FASD. Ashurst Australia explained that mental impairment can be recognised as a defence under both the *Criminal Code Act 1995 (Cth)* in the higher courts and the *Crimes Act 1914 (Cth)* in the lower courts.¹²² However, the definition of 'mental impairment' differs; in the former, mental impairment includes brain damage, which could apply to people with FASD, whereas the latter only provides for defendants with a mental illness or intellectual disability.¹²³

119 Dr D Hartman, Consultant, Townsville Child and Youth Mental Health Service, *Committee Hansard*, Townsville, 31 January 2012, p. 21.

120 R Denfeld, *Catching the Subtle Signs of Cognitive Impairment, FASD, and other "Invisible" Disabilities*, 2011, Library of Defense <www.libraryofdefense.org> viewed 22 October 2012.

121 Ashurst Australia, *Submission 49*, p. 24.

122 Ashurst Australia, *Submission 49*, p. 24.

123 Ashurst Australia, *Submission 49*, p. 24. Ashurst Australia further notes that the proportion of people dealt with in courts of summary jurisdiction compared to higher courts means that the limited definition under the *Crimes Act 1914 (Cth)* has a broader impact.

- 5.107 As discussed earlier, individuals with FASD have brain damage that affects their cognitive development, but may not necessarily have an intellectual disability or a mental illness. Such defendants would then be 'precluded from having their lesser culpability taken into account in the lower courts when charged with a federal offence'.¹²⁴ Similar inconsistencies occur in state and territory criminal law systems.¹²⁵
- 5.108 In an article on FASD and the criminal justice system, Associate Professor Heather Douglas observed that intellectual disability has been accepted as a mitigating factor of reduced culpability in Australia. However, in these cases intellectual disability has been defined as 'below average intelligence', which would exclude people with FASD who have normal intelligence despite a lowered cognitive capacity.¹²⁶
- 5.109 Aboriginal Peak Organisations Northern Territory (APONT) submitted that people suspected of having developmental or cognitive impairments will 'enter the criminal justice system without appropriate consideration of their impaired functioning by the court'.¹²⁷ The Aboriginal Disability Justice Campaign emphasised the need for 'understanding that there are in fact these categories of people that are not culpable for their actions'.¹²⁸
- 5.110 Individuals who have lesser or no culpability for criminal offences should be treated rather than imprisoned. However, diverting individuals with FASD from the criminal justice system can be difficult when FASD is not recognised as a disability.
- 5.111 Legal aid services note that the lack of diagnostic criteria in Australia leaves individuals with FASD to 'fall between the cracks in terms of diversion into treatment'.¹²⁹
- 5.112 Moreover, there are few diversionary programs available for people with FASD, as it is a non-recognised and under-diagnosed disability. The lack of diversionary options limits the sentencing options for people diagnosed with, or suspected of having, FASD. The APONT stated that:

Without a formal medical diagnosis of FASD, it is difficult for magistrates to rely upon impaired functioning as a mitigating factor in sentencing. Moreover, the dearth of specific management

124 Ashurst Australia, *Submission 49*, p. 24.

125 Ashurst Australia, *Submission 49*, p. 24.

126 H Douglas, *The sentencing response to defendants with foetal alcohol spectrum disorder*, 2010, 34 Crim LJ 221, p. 231

127 J Paterson, Chief Executive Officer, Aboriginal Medical Services Alliance Northern Territory, *Committee Hansard*, Darwin, 21 June 2012, p. 16.

128 P McGee, ADJC, *Committee Hansard*, Sydney, 13 April, p. 20.

129 Joint Legal Aid, *Submission 44*, p. 7.

services or a centre to coordinate access to community services that may assist an individual with FASD, provide few options for magistrates to effectively and creatively sentence offenders with FASD before the courts. Consequently, sentencing dispositions are rarely able to reflect the difficulties experienced by FASD affected individuals and instead offenders with FASD are subject to the same sentences and punishments, such as imprisonment, as fully functioning offenders, despite this being inappropriate.¹³⁰

Actions

5.113 In North America, FASD is recognised as a mitigating factor that must be taken into account in sentencing.¹³¹ Associate Professor Douglas noted that:

The explicit identification of FASD in sentencing judgements may help to establish a consistent and appropriate approach to sentencing and may also assist in drawing attention to the need for specific services for this group of offenders.¹³²

5.114 Ashurst Australia concurs, arguing that:

For a defendant, the identification of FASD may enable:

- appropriate assistance to be provided to enable the person to better understand the process and their options;
- avoidance of miscarriages of justice arising from the fact that the person does not understand what is being asked of him or her or cannot respond as required by the system;
- diversion from the criminal justice system;
- any reduction in culpability on account of their FASD to be considered in determining the person's guilt or innocence or in sentencing;
- support to be provided to a person to carry out their sentence without being set up to fail; and
- any symptoms of FASD which are causing the person's offending behaviour to be addressed.¹³³

5.115 Some steps have been taken in this direction by the Western Australia Supreme Court, which is the first to include FASD in its *Equality Before the*

130 Aboriginal Peak Organisations Northern Territory, *Submission 38*, p. 20.

131 H Douglas, *The sentencing response to defendants with foetal alcohol spectrum disorder*, 2010, 34 Crim LJ 221, p. 231.

132 H Douglas, *The sentencing response to defendants with foetal alcohol spectrum disorder*, 2010, 34 Crim LJ 221, p. 235.

133 Ashurst Australia, *Submission 49*, p. 23.

Law Bench Book.¹³⁴ Such bench books provide legal practitioners with information that enables them to identify disadvantages that need to be addressed to ensure equal treatment of all individuals. Dr Raewyn Mutch explained:

... we know that these people are in the system, and you cannot offer them equity before the law easily because of their cognitive impairment ... So I wrote to the WA Chief Justice – a remarkable man – and his immediate response was: ‘I fully support you in this endeavour. Here are your letters of introduction to every single criminal body. Could you please provide us more information? We will put that information into our *Equality Before the Law Bench Book*.’ ... So now in this state ... any person who presents to a court, if they have been afforded the diagnosis of FASD, which has not happened very often yet, potentially will be treated with equity before the law.¹³⁵

5.116 However, in law people with FASD are potentially excluded from recognition of their limited competency or from diversionary sentences. Accordingly, Ashurst Australia recommended:

That the threshold criteria for diversion from the criminal justice system and for a person’s disability to be taken into consideration in criminal proceedings be amended in the Commonwealth criminal law to ensure people with FASD can fall within the relevant legislative provisions.¹³⁶

5.117 Ashurst Australia considers that the term ‘cognitive impairment’ is the most appropriate, broadest definition to use in legislation in place of intellectual disability or impairment.¹³⁷

5.118 Ashurst Australia does not believe that using the term ‘cognitive impairment’ would increase the numbers of people eligible for consideration of reduced culpability in the courts, as people with FASD would still have to:

... prove that they have a particular type of illness or disability and that they have functional impairments to a requisite degree. We say that the definition of cognitive impairment should be that

134 Western Australia Department of the Attorney-General, *Equality Before the Law Bench Book*, 2009, <www.supremecourt.wa.gov.au/_files/equality_before_the_law_benchbook.pdf> viewed 5 November 2012.

135 Dr R Mutch, *Committee Hansard*, Perth, pp. 24–25.

136 Ashurst Australia, *Submission 49*, p. 25.

137 M Seely, Ashurst Australia, *Committee Hansard*, Sydney, 13 April 2012, p. 19.

threshold. It would be broadening the threshold yet relying on a test of the actual impairment that a person lives with.¹³⁸

Identifying FASD as a disability

5.119 Formally recognising FASD as a disability is seen as the key that unlocks the door to support and assistance for those living with FASD:

It means that ... schools will get support and children will get support in schools. It also means that families will get support. It means that people with a disability themselves can get support throughout their lives. It means that justice outcomes will be fair and equal because of this disability if it is recognised. It means that people with this disability throughout their adult lives can not only get the support they need but make the contributions to their communities that they want to make.¹³⁹

5.120 Ashurst Australia acknowledged that:

People who care for or work with people with FASD consistently tell us that one of the things which must change if people with FASD are to receive the support they need is that FASD needs to be recognised by government as a disability. We hear of people denied benefits and services on the basis that a diagnosis of FASD does not qualify them for the support they are seeking.¹⁴⁰

5.121 Submitters to the inquiry consistently advocated for FASD to be recognised as a disability on the List of Recognised Disabilities.¹⁴¹ This would enable carers of children with FASD to automatically receive the Carer Allowance, in the same way that carers of children with Down syndrome or cystic fibrosis automatically receive the Carer Allowance.

138 M Seely, Ashurst Australia, *Committee Hansard*, Sydney, 13 April 2012, p. 19.

139 M White, *Committee Hansard*, Mimbì, 11 July 2012, p. 4.

140 Ashurst Australia, *Submission 49*, p. 7.

141 Catholic Education Office, *Submission 5*, p. 1; NCID, *Submission 9*, p. 7; Legal Aid NSW and Aboriginal Legal Service NSW/ACT, *Submission 44*, p. 8; Dr R Chataway, *Committee Hansard*, Townsville, 31 January 2012, pp. 14, 20; NOFASARD, *Submission 46*, p. 5; WA Health Country Health Service – Kimberley Population Health Unit Response, *Submission 31*, p. 3; FARE/PHAA, *Submission 36*, p. 6; Australian Women’s Health Network, *Submission 58*, p. 5; Telethon Institute, *Submission 23*, p. 4; Australian Indigenous Doctors Association, *Submission 67*, p. 2; Fetal Alcohol Spectrum Disorder Research Network, *Submission 47*, p. 2; ADCA, *Submission 33*, p. 12; Ashurst Australia, *Submission 49*, p. 19.

- 5.122 Moreover, the impairments associated with FASD need to be treated as seriously as those associated with low IQ, mental illness and psychiatric disorders. Ashurst Australia stated that:
- ... people with other forms of cognitive disability or impairment are often ineligible for benefits which are available to people with mental illness or intellectual disability. They may also fall outside diversionary and other criminal laws which reflect the lesser culpability of a person with mental illness or cognitive disability.¹⁴²
- 5.123 Broadening the definition of disabilities in relevant legislation to include the entire spectrum of severe impairments that affect people with FASD would address this inequity. At present, the terms 'intellectual disability', 'intellectual impairment', 'mental illness' and 'psychiatric illness' do not necessarily encompass a person with FASD, nor others with cognitive deficiencies such as acquired brain injury.¹⁴³
- 5.124 The Committee heard that a favoured term is 'cognitive impairment', which:
- ... encompasses, but is not limited to, intellectual impairment, and is not measured by reference to IQ. The American Psychiatric Association in its *Diagnostic and Statistical Manual of Mental Disorders (DSM- IV-TR)* stated that generally, a cognitive impairment or disorder means a loss of brain function affecting judgment and resulting in a decreased ability to process, learn or remember information.¹⁴⁴
- 5.125 The Telethon Institute agreed that cognitive impairment is a more effective measurement of disability, particularly as individuals with FASD may not have a low IQ, and that legislation should be amended accordingly.¹⁴⁵
- 5.126 Ashurst Australia concluded that the Commonwealth Government should lead the way in the use of the term 'cognitive impairment' as a model definition in the appropriate legislation.¹⁴⁶
- 5.127 Consequently, Ashurst Australia advocated for:
- A nationally consistent definition, which is not exhaustive but which provides strong guidance to those implementing the law and policy, would increase certainty for government and people

142 Ashurst Australia, sub 49, p. 7.

143 Ashurst Australia, sub 49, p. 9.

144 Ashurst Australia, *Submission 49*, p. 9.

145 H Jones, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 23.

146 M Seely, Ashurst Australia, *Committee Hansard*, Sydney, 13 April 2012, p. 19.

with FASD about when particular laws and policies apply to people with FASD. It would also assist to remove the barriers faced by people with FASD to the support and services they need.¹⁴⁷

Committee Comment

- 5.128 The critical importance of diagnosis was explored in the previous chapter. However, diagnosis is only part of the answer for people with FASD and their families; they must have access to support and management for their disabilities and any secondary conditions for their entire lives.
- 5.129 The Committee heard from a range of witnesses about the difficulties in obtaining financial, educational and justice support for people with FASD.
- 5.130 These difficulties stem from two main problems – lack of understanding of FASD and lack of recognition of FASD as a disability. The Committee considers that improving these two deficiencies will lead to greater awareness of FASD as well as boost funding, research, pilot studies and programs, and policies for FASD support and management strategies.
- 5.131 The Committee advocates for improved understanding and knowledge of FASD, particularly in the education and criminal justice sectors. The behavioural issues that people with FASD may exhibit need to be recognised as disabilities arising from prenatal alcohol exposure, rather than naughty, anti-social or criminal conduct.
- 5.132 The Committee commends the examples of state resources for teachers and judicial officers referred to in this chapter. In line with the Committee’s stance on a cohesive, national FASD strategy, the Committee considers that the production and dissemination of educational material should be managed at a national level rather than left to the political will and resources of each state.

Recommendation 17

- 5.133 **The Committee recommends that the Commonwealth Government develop educational material to raise awareness about Fetal Alcohol Spectrum Disorders (FASD). These materials should be monitored and informed by the FASD Reference Group.**

147 Ashurst Australia, *Submission 49*, p. 10.

In particular, targeted training and materials should be developed for:

- special education teacher aides and class teachers;
- parents, foster carers and foster care agencies;
- police and court officials;
- youth workers and drug and alcohol officers; and
- officers in correctional facilities and juvenile detention centres.

- 5.134 Establishing FASD as a recognised disability would increase awareness and knowledge of FASD. The Committee is disappointed that the recommendation made by the Standing Committee on Aboriginal and Torres Strait Affairs in 2011 for FASD to be added to the List of Registered Disabilities was not accepted by the Commonwealth Government.¹⁴⁸
- 5.135 The Committee finds it inequitable that people with FASD, who often require high levels of care and have significant cognitive impairments, are not eligible for support services in the disability and education sectors in the same way that people with other disabilities are. People with FASD are no less deserving or in need of disability income support or educational assistance and resources.
- 5.136 The Committee is concerned that the reduced culpability of individuals with FASD may not be taken into account in judicial courts, resulting in such people being imprisoned instead of treated.
- 5.137 The Committee received compelling evidence that legislating a clear and inclusive definition of disability would remove the confusion around the eligibility of individuals with FASD for support services and ensure equity before the law for defendants with FASD.

Recommendation 18

- 5.138 **The Committee recommends that the Commonwealth Government include Fetal Alcohol Spectrum Disorders in the List of Recognised Disabilities and the Better Start for Children with a Disability Initiative.**

¹⁴⁸ Parliament of Australia, Standing Committee on Aboriginal and Torres Strait Islander Affairs, *Doing Time – Time for Doing: Indigenous youth in the criminal justice system*, June 2011, p 103.

Recommendation 19

- 5.139 **The Committee recommends that the Commonwealth Government recognise that people with Fetal Alcohol Spectrum Disorders have, amongst other disabilities, a cognitive impairment and therefore amend the eligibility criteria to enable access to support services and diversionary laws.**