

Diagnosis

- 4.1 This chapter discusses some of the obstacles to improving the diagnosis and management of Fetal Alcohol Spectrum Disorders (FASD) in Australia.
- 4.2 Early intervention is a critical factor in ameliorating both the primary and secondary symptoms of FASD, therefore the ability to recognise and diagnose FASD at a young age is important. In cases where prenatal alcohol exposure has occurred, all instances of FASD need to be diagnosed.
- 4.3 Currently there are a number of obstacles to comprehensive FASD diagnosis. The chapter addresses how perceived stigma, limited understanding and capacity of some health professionals, the complexity of FASD, and the lack of a national diagnostic tool and diagnostic clinics hinder the opportunities for a person with FASD to be diagnosed accurately.
- 4.4 It is also essential that therapeutic intervention services are properly-funded and available to all who have been disabled by fetal alcohol exposure. At present, the training and capacity of general practitioners, paediatricians and allied health professionals to manage FASD is limited.

Critical importance of early diagnosis and intervention

- 4.5 It is of critical importance that FASD is diagnosed as early as possible to enable the individual to receive the accurate intervention and

understanding. A foster carer warned that ‘failure to recognise, diagnose and understand this disorder has huge ramifications for all society’.¹

4.6 Without an accurate diagnosis, the problems exhibited by individuals with FASD may be misunderstood as a different condition. This can result in the incorrect treatment or patient care and increase the risk of developing secondary conditions.²

4.7 A number of carers and people involved in child protection confirmed to the Committee the cost of delayed or incorrect diagnosis. Barbara Smith explained that:

Instead of understanding the child and catering for their [FASD] needs these children were given little appropriate support. Now as adults they have dropped out of school, suffered relationship difficulties, homelessness, mental health issues, antisocial behaviour and unemployment. With recognition and appropriate intervention they may have achieved much more.³

4.8 Prue Walker stated that:

Without an understanding of FASD, interventions are likely to be counter-productive as the young person engages in a service system which promotes a model of increasing self reliance and independence, a goal which is not often appropriate for a young person with a lifelong brain-based condition that impairs judgement and decision making.⁴

4.9 Anne Russell’s work with the Russell Family Fetal Alcohol Disorders Association (RFFADA) involves educating people about FASD and the importance of early intervention. She stated that:

Early intervention has been shown to make a huge difference in the life of a child with FASD, so we need early diagnosis, early intervention and understanding by all the people around that person that their brain works differently. Among the things that really make a negative difference to a person with FASD are the expectations of other people. The expectations of somebody who does not look different and who, on the surface, can talk quite well are that they can do what everybody else can do when in fact they cannot, so their experience of the world from when they are young is failure after failure. Consequently – though this is not the only

1 B Smith, *Submission 4*, p. 1.

2 A E Chudley et al, ‘Fetal Alcohol Spectrum Disorder: Canadian guidelines for diagnosis,’ *Canadian Medical Association Journal*, vol. 172 (5 suppl), March 2005, p. S2.

3 B Smith, *Submission 4*, p. 1.

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

reason – they are drawn to criminal activities, because that is a place where they belong. So early intervention can prevent an awful lot and save an awful lot of money down the track.⁵

- 4.10 Upon finally having FASD confirmed for her daughter on a trip to Canada, Sue Miers said:

I was, of course, relieved to learn that my daughter's developmental and behavioural problems were most likely based in organic brain damage rather than being intentional or the result of my poor parenting, which I was beginning to feel at that stage. I also felt a great sadness as I realised the frustration she must have experienced during a lifetime of failure, being told to do better when in reality she was unable to do so. She was being the best she could be, despite school reports to the contrary. I realised my expectations of her would have to change dramatically, and I realised what a difference it could have made to her life if I had had that knowledge during her formative years. I grieved for her lost potential and opportunity, and wondered why I had had to travel to Canada to get information and support that should have been available in Australia.⁶

- 4.11 Prue Walker noted that young people with FASD who did not receive the appropriate management are 'likely to enter the care system as an angry, confused young adult who has had negative experiences at school, at home and among peers'.⁷

- 4.12 Although FASD cannot be cured, there is overwhelming evidence that accurate, early diagnosis, followed by appropriate intervention, can be successful in achieving better outcomes for children with FASD, as 'some symptoms can be remediated partially through early intervention'.⁸

- 4.13 Barnardos discussed a foster child who has benefited enormously from early diagnosis and management:

Because she got that diagnosed at a really young age, at 13 months, there was a lot of intervention put in place with speech therapy, occupational therapy, physiotherapy and regular paediatric reviews. That has assisted her to make enormous gains. She is now sort of functioning at a level where there are still some

5 A Russell, Executive Officer, The Russell Family Fetal Alcohol Disorders Association (RFFADA), *Committee Hansard*, Cairns, 31 July 2012, p. 5.

6 S Miers, Chair, National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD), *Committee Hansard*, Melbourne, 22 June 2012, p. 18.

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

8 Australian National Preventative Health Agency (ANPHA), *Submission 45*, p. 3.

issues with her speech and language and she does present with behaviours that you would associate with [Attention Deficit Hyperactivity Disorder] but we have got huge hope for her prospects for the future and the possibility of adoption down the track for her with her permanent foster carers.⁹

- 4.14 UnitingCare offers an Intensive Playgroup that provides important skills for children with FASD who might not fit in at school:

... it addresses some of the issues for young children, like being able to share, to sit in a room with other children, to play, to listen, to read and to sing. These are the sorts of behaviours that make these kids, when they start kindergarten and school, stand out already as being the problem kids.¹⁰

- 4.15 Moreover, early intervention may substantially reduce the risk and impact of secondary social, emotional and behavioural difficulties.¹¹ Sue Miers regrets that her 'daughter's diagnosis came too late to give us the knowledge we needed that may have helped prevent the many secondary disabilities she has since experienced'.¹²
- 4.16 Screening for mothers and children at risk can detect FASD at an early stage and improve the chances of individuals with FASD receiving early intervention.
- 4.17 The Royal Australasian College of Physicians (RACP) recommended screening for all children who come into contact with an obstetric drug dependency service, child protection service, or the criminal justice system.¹³ The Western Australia FASD Working Party proposed direct links between child welfare and early intervention services.¹⁴
- 4.18 Screening for alcohol consumption could be conducted for all women during pregnancy, and screening of all children at birth and at enrolment

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

10 D J Ribton-Turner, Director, Clinical Services, UnitingCare ReGen, Uniting Church in Australia Synod of Victoria and Tasmania, *Committee Hansard*, Melbourne, 22 June 2012, p. 26.

11 For example see, South Australian Government, *Submission 52*, p. 4; A Russell, RFFADA, *Committee Hansard*, Cairns, 31 January 2012, p. 5; National Council on Intellectual Disability, *Submission 9*, p. 5; Alcohol and other Drugs Council of Australia, *Submission 33*, p. 2; Northern Territory branch of the Public Health Association of Australia, *Submission 73*, p. 2; Foundation for Alcohol Research and Education/Public Health Association of Australia (FARE/PHAA), *Submission 36*, p. 10; National Rural Health Association (NRHA), *Submission 40*, p. 15; NOFASARD, *Submission 46*, p. 11.

12 S Miers, NOFASARD, *Committee Hansard*, Melbourne, 22 June 2012, p. 19.

13 Royal Australasian College of Physicians, *Submission 27*, p. 4.

14 Fetal Alcohol Spectrum Disorders Working Party, Department of Health, Western Australia, *Submission 25*, p. 2.

in school.¹⁵ The National Organisation for Fetal Alcohol Syndrome and Related Disorders (NOFASARD) further suggested that children in child and family centres could be screened.¹⁶

4.19 John McKenzie noted that:

There is already testing on entry into kindergarten. That should be included so that there is some FASD type of [screening] component to that. Then you move on, to the kids who are in out-of-home care.¹⁷

Obstacles to diagnosis

4.20 It cannot be emphasised enough that a diagnosis is crucial to improving the life trajectory of individuals with FASD and their families. NOFASARD stated that 'diagnosis gives visibility, and visibility expands options and leads to solutions'.¹⁸

4.21 The National Council on Intellectual Disability noted a number of benefits from diagnosing FASD:

- Early diagnosis is a protective factor associated with fewer secondary disabilities;
- 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; and
- Diagnosis of one child may mean successful intervention with the mother to prevent the birth of another child with FASD.¹⁹

4.22 Dr Raewyn Mutch advised the Committee that the ideal scenario would be a 'broad spectrum of health care' that provides national uniformity of diagnosis, training and management teams.²⁰

15 WA Health, Health Networks Branch (Child and Youth Health Network), *Submission 13*, p. 6.

16 NOFASARD, *Submission 46*, p. 6.

17 J McKenzie, Chief Legal Officer, Aboriginal Legal Service (New South Wales and the Australian Capital Territory), *Committee Hansard*, Sydney, 13 April 2012, p. 21.

18 S Miers, NOFASARD, *Committee Hansard*, Melbourne, 22 June, p. 19.

19 National Council on Intellectual Disability, *Submission 9*, pp. 6-7.

20 Dr R Mutch, Telethon Institute for Child Health Research (Telethon Institute), *Committee Hansard*, Perth, 10 July 2012, p. 23.

- 4.23 Unfortunately, the Committee heard that there are many obstacles to obtaining a diagnosis in Australia. These include the stigma attached to acknowledging maternal alcohol consumption; low level of knowledge among health professionals; the scope and complexity of the FASD spectrum; lack of a nationally-recognised diagnostic tool; and lack of diagnostic services. This section addresses these obstacles.

Stigma

- 4.24 The Committee heard that health professionals can be reluctant to consider or diagnose FASD because it is a highly stigmatising label.²¹
- 4.25 Di Harriss stated that such reluctance can have significant implications for children who are then deprived of 'appropriate and effective early interventions in order to maximise the child's potential to address the disabilities, and associated problems'.²²
- 4.26 A foster carer related his experience with a doctor who was reluctant to discuss FASD:
- Actually, he might have said once, 'Why would you want that diagnosis?' I said, 'Because it would help me know what is wrong with him.' I think it is a bit like HIV. People would say, 'Why would you want your child to be diagnosed?'²³
- 4.27 Anecdotal evidence suggested a preference for a diagnosis of Attention Deficit/Hyperactivity Disorder, Autism Spectrum Disorder or general developmental delay, even in the case of confirmed prenatal alcohol exposure.²⁴
- 4.28 The Australian National Preventive Health Agency considers that better education of health professionals with a focus on prevention rather than cure could help with the stigma. They contend that not having to focus on a particular outcome or condition will enable health professionals to talk about the benefits of reducing harmful alcohol consumption for a whole range of outcomes without having to point the finger at particular children or particular conditions.²⁵
- 4.29 Prue Walker, when undertaking her Churchill Fellowship in the US and Canada, found that instead of being stigmatising, diagnosis could be

21 Dr L Studdert, ANPHA, *Committee Hansard*, Canberra, 15 March, p. 1; Anyinginyi Health Aboriginal Corporation, *Submission 3*, p. 2.

22 D Harriss, *Submission 69*, p. 1.

23 L Chataway, *Committee Hansard*, Townsville, 31 January, p. 14.

24 Anyinginyi Health Aboriginal Corporation, *Submission 3*, p. 2; Dr Chataway, *Committee Hansard*, Townsville, 31 January 2012, p. 13; R and L Chataway, *Submission 7*, p. 1.

25 Dr L Studdert, ANPHA, *Committee Hansard*, Canberra, 15 March 2012, p. 4.

liberating for families who were struggling to understand and manage their children.²⁶

4.30 In contrast, Dr David Hartman registered his concern that FASD could be over diagnosed where it is required to access resources 'because people would, quite rightfully, be seeking out help for their children'.²⁷

4.31 Dr Mutch believes that it is possible for the perceived stigma around FASD to be minimised, as it has in the case of ASD:

Autism was perceived as a diagnosis to be feared, I think. Now, in some places, it is a diagnosis that is warmly embraced because it is chased with high-level care and guaranteed aid and education. The stigma has fallen away as support, understanding and research has been provided, and allowing people to have this condition has elevated it to normality not stigma.²⁸

4.32 Dr Mutch further predicted that:

... if you allow [FASD] children to be diagnosed and you chase this with appropriate educational support and appropriate therapeutic intervention, you will unlock the legitimacy and the okay for having this diagnosis.²⁹

Current capacity of health professionals to diagnose FASD

4.33 The Telethon Institute for Child Health Research (Telethon Institute) stated that there is good evidence indicating that FASD is poorly recognised in Australia and diagnoses can often be missed or delayed. They attributed this to health professionals' reluctance to ask about alcohol use and lack of knowledge about the clinical indications of FASD.³⁰

4.34 NOFASARD provided the Committee with one family's unsuccessful experience with health professionals:

I have an 11 year old adopted son whom I suspect suffers with some form of FASD. I have been from doctor to doctor only to be told by one paediatrician that it was unlikely to be that even after we [told him the child's] birth mother ... admitted to drinking a lot of alcohol during her pregnancy, daily even. I learnt about FASD

26 P Walker, *To study models of care for children with Foetal Alcohol Syndrome*, 2008, p. 17; Winston Churchill Memorial Trust, <http://www.churchilltrust.com.au/site_media/fellows/Walker_Prudence_2008.pdf> viewed 14 August 2012.

27 Dr D Hartman, Consultant Child and Adolescent Psychiatrist, Townsville Child and Youth Mental Health Service, *Committee Hansard*, Townsville, 31 January 2012, p. 20.

28 Dr R Mutch, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 26.

29 Dr R Mutch, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 26.

30 Telethon Institute, *Submission 23*, p. 1.

about a couple of years ago and since then have been trying to find a doctor who is aware of this.³¹

- 4.35 The Committee heard from many submitters that there is a need for more FASD training for health professionals. Professor Elizabeth Elliott acknowledged that FASD was not covered in the medical curricula that she studied in the late 1970s, although there was exposure to the condition through paediatric training in hospital.³² Dr Mutch confirmed that ‘there still is no mandatory teaching of about FASD within medical training at all’.³³
- 4.36 An Apunipima Cape York Health Council report suggested that FASD should constitute one of the medical training modules for doctors, nurses and Indigenous health workers.³⁴ In addition to medical school curricula, the Alcohol and other Drugs Council of Australia recommended that FASD be introduced to the training for health professionals working in the alcohol and other drug sector.³⁵ The RACP recommended:
- ... formal training of a range of health professionals including community nurses, allied health professionals, general practitioners, paediatricians, physicians and psychiatrists to better identify and diagnose FASD and to recognise the needs of the diagnosed individuals.³⁶
- 4.37 A Western Australian FASD Prevention Aboriginal Consultation Forum identified a lack of FASD training opportunities and limited resources for regional and non-maternal health environments.³⁷
- 4.38 In the Northern Territory, the Child and Adolescent Mental Health Team acknowledged that:
- ... through recent readings, discussion and through our practical experiences and observations we have come to realise that FASD has not been a widely discussed phenomenon within our work community.³⁸
- 4.39 A study, which looked at paediatricians’ knowledge, attitudes and practice after being given educational resources about preventing prenatal

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

32 Professor E Elliott, Professor of Paediatrics and Child Health, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 6.

33 Dr R Mutch, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 23.

34 E Pearson, *Submission 48*, p. 8.

35 Alcohol and other Drugs Council of Australia, *Submission 33*, p. 11.

36 Royal Australasian College of Physicians, *Submission 27*, p. 4.

37 ANPHA, *Submission 45*, p. 4.

38 Top End Mental Health Service, *Submission 83*, p. 1.

alcohol exposure and FASD, found that asking women about alcohol use during pregnancy should be emphasised in paediatric training. It concluded that, unless paediatricians' capacity to recognise and diagnose FASD is improved, FASD 'will remain under-diagnosed in Australia and opportunities for management, early intervention and prevention will be overlooked'.³⁹

Figure 4.1 Russell Family Fetal Alcohol Disorders Association

RFFADA, the Russell Family Fetal Alcohol Disorders Association, is a not-for-profit health promotion charity dedicated to ensuring that individuals affected prenatally by alcohol have access to diagnostic services, support and multidisciplinary management planning in Australia and that carers and parents are supported with a 'no blame no shame' ethos. Their mission is to provide information, training and education to increase the capacity of communities, organisations and individuals to support those people living with FASD to live to their full potential.

Based in Brisbane, RFFADA was founded by Elizabeth Anne Russell, whose two children were diagnosed with a FASD. Mrs Russell has authored several books on FASD and promotes FASD training for health professionals, educators, and others who come into contact with people living with FASD.

Mrs Russell said, 'I could not find medical professionals who understood the condition, so in 2007 I established the Russell Family Fetal Alcohol Disorders Association and since then I have been liaising with people and organisations around Australia.'

Source: <http://www.rffada.org/> and <http://www.elizabethrussell.com.au/home/> and Committee Hansard, Cairns, 31 January 2012, pp. 1.

4.40 It is not expected that a single health practitioner would diagnose FASD. Dr Mutch, a paediatrician, acknowledged that:

I as a doctor feel I cannot diagnose FASD on my own. I need the skills of my allied health team to inform me about the jigsaw puzzle of the child before me.⁴⁰

However, all health practitioners need to be aware of the risks and symptoms of FASD so that an early referral can be made to the appropriate specialists.

39 J M Payne et al, 'Paediatricians' Knowledge, Attitudes and Practice Following Provision of Educational Resources about Prevention of Prenatal Alcohol Exposure and Fetal Alcohol Spectrum Disorder', *Journal of Paediatrics and Child Health*, vol. 47, no. 10, 2011, p. 6.

40 Dr R Mutch, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 23.

- 4.41 Prue Walker explained that without knowledge of FASD, health professionals may only consider individual behaviour and development in isolation without reference to the impact of prenatal alcohol exposure and the spectrum of effects.⁴¹
- 4.42 Professor Elliott pleaded the case for a 'concerted national effort':
- We need to identify and train up teams that could be either based in individual states and/or be mobile clinics that could service communities that are in need. The longer we delay, the greater the number of children that will be born with foetal alcohol spectrum disorders.⁴²
- 4.43 The joint submission from the Foundation for Alcohol Research and Education and Public Health Association of Australia advocated for funding allocation to 'train health professionals working in multi-disciplinary teams to have the capacity to diagnose FASD'.⁴³

Complexity of FASD

- 4.44 As described earlier, there are a number of diagnoses under the umbrella of FASD. The range of conditions, and their even greater range of symptoms and indications, can be challenging to diagnose. Dr Susan Astley from the University of Washington, a leading organisation for research into FASD, wrote that:
- Individuals with prenatal alcohol exposure present with a wide range of outcomes, most of which are not specific to prenatal alcohol exposure and often manifest differently across the lifespan. ... The pattern and severity of outcomes are dependent on the timing, frequency, and quantity of alcohol exposure (which is rarely known with any level of accuracy), and is frequently confounded by other adverse prenatal and postnatal exposures and events.⁴⁴
- 4.45 FASD conditions that do not feature characteristic facial abnormalities can be difficult to diagnose as none of the other characteristic problems are unique to FASD; all can be associated with other factors, such as low

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

42 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 3.

43 FARE/PHAA, *Submission 36*, p. 21.

44 S J Astley, 'Diagnosing Fetal Alcohol Spectrum Disorders (FASD)', in S A Adubato and D E Cohen, eds, *Prenatal Alcohol Use and Fetal Alcohol Spectrum Disorders: Diagnosis, assessment and new directions in research and multimodal treatment*, Bentham Books, Oak Park, 2011, p. 3.

socio-economic status and poor maternal nutrition.⁴⁵ Professor Elliott explained:

That is where the confounding comes in. How can you attribute those developmental problems to alcohol, particularly if there are other issues in the family? That is the thing that clinicians grapple with. The approach we have taken is to do a very comprehensive assessment of speech and language, fine motor skills, gross motor skills, learning, IQ et cetera.⁴⁶

4.46 Moreover, 'invisible' damage to the central nervous system may not manifest until a child starts school and demonstrates learning or behavioural difficulties.⁴⁷

4.47 Individuals with FASD may have other medical conditions that complicate the recognition of FASD. For example, Tracey Harth acknowledged that for her foster son:

... a diagnosis of FASD would be hard to get because there were so many different things that were being abused at the [pregnancy] so he cannot be put into that small little box and he might be a bit wider on the spectrum.⁴⁸

4.48 Associate Professor Heather Douglas found that the complexity of a diagnostic process means that several appointments with different professionals may be required. Yet, the deficiencies of attention and planning that are linked to FASD may make completion of the diagnosis difficult without adequate support.⁴⁹

4.49 When individuals present with secondary disabilities, which can be caused by any number of factors, finding the correct diagnosis can be even more difficult.⁵⁰

4.50 Extensive assessments are required to rule out other conditions and to determine an individual's dysfunction. Dysfunction in three domains of the central nervous system constitutes one of the criteria for FASD, but all domains must be tested as each individual could present with a different combination of deficiencies. This cannot be accomplished by a single

45 Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders, *Fetal Alcohol Spectrum Disorders: An Update*, 2009, p. 36.

46 Professor E Elliott, University of Sydney, *Committee Hansard*, Canberra, 24 November 2011, p. 4.

47 R Mutch et al, 'Need to establish a National Diagnostic Capacity for Foetal Alcohol Spectrum Disorders', *Journal of Paediatrics and Child Health*, vol. 45, no. 3, 2009, pp. 79-81.

48 T Harth, Foster Carer, Barnardos, *Committee Hansard*, Sydney, 13 April 2012, p. 33.

49 H Douglas, 'The Sentencing Response to Defendants with Foetal Alcohol Spectrum Disorder', *Criminal Law Journal*, vol. 34, 2010, p. 226.

50 Catholic Education Office of Western Australia, *Submission 5*, p. 1.

practitioner or even by several practitioners working in isolation from each other.

- 4.51 At the pilot diagnostic clinic at Westmead Hospital in Sydney and the Fitzroy Valley clinic, assessments are made by multiple medical staff from a wide range of disciplines who work together to reach a diagnosis and recommend a management plan. These assessments take four to eight hours per child.⁵¹

Nationally consistent diagnostic tool and guidelines

- 4.52 A number of diagnostic guidelines or criteria for FASD were created in North America that are currently used internationally:
- The United States Institute of Medicine;
 - Washington State 4-digit Diagnostic Code;
 - Hoyme revision of Institute of Medicine criteria;
 - The United States Center for Disease Control;⁵² and
 - The Canadian Guidelines.⁵³
- 4.53 An international survey of diagnostic clinics found that they used either one set or combined multiple sets of the above guidelines, sometimes with modifications, to aid diagnosis.⁵⁴
- 4.54 At present, Australia does not have nationally-agreed diagnostic criteria or guidelines. A 2008 study of Australian health professionals endorsed the need for national diagnostic guidelines for FASD, and the need for their evaluation in the Australian context to ensure that the guidelines are feasible, nationally applicable, valid, and acceptable to both health professionals and consumers.⁵⁵
- 4.55 In 2010, the Australian FASD Collaboration (the Collaboration) undertook the FASD Project, tasked with developing an instrument for standardising the screening and diagnosing of FASD in Australia. The Collaboration includes medical specialists, paediatricians, researchers and academics,

51 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 4.

52 E Peadon et al, 'International Survey of Diagnostic Services for Children with Fetal Alcohol Spectrum Disorders', *BMC Pediatrics*, vol. 8, 2008.

53 S J Astley, 'Diagnosing Fetal Alcohol Spectrum Disorders (FASD)', p. 16.

54 E Peadon et al, 'International Survey of Diagnostic Services for Children with Fetal Alcohol Spectrum Disorders', *BMC Pediatrics*, vol. 8, 2008.

55 E Peadon et al, 'International Survey of Diagnostic Services for Children with Fetal Alcohol Spectrum Disorders', *BMC Pediatrics*, vol. 8, 2008.

and consumer and community representatives from across the country.⁵⁶
The Collaboration collected data which:

... supported the need for standard, locally appropriate and evidence based diagnostic criteria and a user-friendly instrument and training resources not only to improve awareness of FASD among health professionals but to improve diagnostic capacity.⁵⁷

- 4.56 The FASD Project was completed in September 2011 and the recommended diagnostic instrument is currently being reviewed by the lead agency, the Department of Health and Ageing (DoHA).
- 4.57 In the meantime, the Sydney and Fitzroy Valley pilot FASD clinics use their own set of criteria, adopted from the Canadian guidelines, which resemble the FASD Project's.⁵⁸

Lack of diagnostic services in Australia

- 4.58 Internationally there are a range of clinics providing diagnostic and assessment services for children exposed to alcohol in pregnancy. The majority of these clinics are located in North America, with some in South Africa, Europe and South America.⁵⁹
- 4.59 A study by Australian researchers into international diagnostic services for FASD found that Australia is lagging behind other countries when it comes to the provision of screening and diagnostic services.⁶⁰
- 4.60 The Catholic Education Office of Western Australia submitted that screening services at present are 'limited, scattered, [and] lacking some coordination'.⁶¹ DoHA agreed that it had received advice indicating that clinical services for FASD 'vary enormously' between states.⁶²
- 4.61 Paediatricians at Royal Darwin Hospital submitted that making a diagnosis is very difficult and 'involves working with multidisciplinary

56 Australian FASD Collaboration, *Submission 19*.

57 Dr R Watkins, Research Fellow, Telethon Institute, *Committee Hansard*, Perth, 10 July 2012, p. 28.

58 Professor E Elliott, University of Sydney, *Committee Hansard*, Canberra, 24 November 2011, p. 3 and *Committee Hansard*, Sydney, 13 April 2012; Dr J Fitzpatrick, Paediatric Senior Registrar/Research Chief Investigator, University of Sydney, Canberra, 24 November 2012, p. 6.

59 Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders, *Fetal Alcohol Spectrum Disorders: An Update*, 2009, p. 82.

60 Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders, *Fetal Alcohol Spectrum Disorders: An Update*, 2009, p. 82.

61 Catholic Education Office of Western Australia, *Submission 5*, p. 1.

62 Dr B Towler, Principal Medical Adviser, Australia Government Department of Health and Ageing, *Committee Hansard*, Canberra, 28 June 2012, p. 14.

teams, which is an informal arrangement in Darwin with community health, occupational therapists, speech therapists and psychologists'.⁶³

4.62 In the absence of multi-disciplinary teams in Central Australia, paediatricians are diagnosing FASD. However, paediatricians are unlikely to be in contact with post-adolescent individuals whose symptoms may not manifest until they are older and bigger.⁶⁴

4.63 Professor Elliott advised the Committee that specialised clinics for FASD are necessary:

These children should be able to be seen in child development clinics, which exist in our major cities; but, if you speak to people who work in and run those clinics, they are absolutely swamped. They try to run a multidisciplinary model, but they are swamped by children with multiple different developmental needs.⁶⁵

4.64 The Committee heard about the diagnostic work that has been conducted in the temporary pilot clinics in Fitzroy Valley and at Westmead Hospital in Sydney, where multidisciplinary teams work together to assess children. For example, in Fitzroy Crossing, a team comprising of a paediatrician, speech therapist, physiotherapist, child psychologist and occupational therapist travelled to the area to undertake an eight hour assessment of each child over two days. In addition, hearing and vision was tested and a comprehensive history of antenatal exposures taken from the parents.⁶⁶

4.65 The Foundation for Alcohol Research and Education (FARE), which funded the Westmead clinic, advised that evaluation of the pilot project will include an assessment of the costs of establishing and maintaining such a screening and diagnostic service.⁶⁷

4.66 Professor Elliott explained that this is a very cost-efficient and satisfactory way of running a clinic:

All the health professionals are there together. We can talk about our findings, we can identify where there is supportive evidence from different assessments, we can come to a joint allocation of a diagnosis and we can develop an individual management plan for

63 Dr L Martin, Paediatrician, Royal Darwin Hospital, *Committee Hansard*, Canberra (Videoconference), 21 June 2012, p. 5.

64 Aboriginal Peak Organisations Northern Territory, *Submission 38*, p. 19.

65 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 4.

66 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 2.

67 FARE/PHAA, *Submission 36*, p. 21.

that child. We are able to provide feedback to the parents within the next couple of days.⁶⁸

- 4.67 Professor Elliott suggested that it was the sort of model that would be appropriate to use in all states. She considers that full-time clinics would not be necessary but it is essential to have a highly trained group of professionals who can work as a team.⁶⁹
- 4.68 Nonetheless, training health specialists in FASD diagnosis is challenging, and even more so for regional and remote areas that already lack adequate health facilities. For example, Warren Harvey explained that:
- We are still on our journey of trying to obtain a complete diagnosis as living approximately 750 km away from Perth [makes this] rather difficult.⁷⁰
- 4.69 Donna Smith from Halls Creek Kimberley Language Resource Centre queried how such an intensive assessment can be achieved in a location where 'it is really hard to even get a post-natal depression assessment. If we are looking at eight hours for one child, it is going to be a big thing'.⁷¹
- 4.70 The Australian Children's Commissioners and Guardians pointed out that given the:
- ... vast distances familiar to many regional areas of Australia and the shortage of skilled professionals ... considerable resourcing to meet the needs of children in regional areas will inevitably be required.⁷²
- 4.71 The Kimberley Population Health Unit noted that a lack of infrastructure in remote communities hindered the attraction and retention of qualified health professionals:
- In places like Fitzroy Crossing, I cannot put a [staff] family in Fitzroy Crossing because I have no houses for a family to live in. People have to share houses, so it only suits single people. So even though we could get extra money for all these positions, you need a whole infrastructure to be part of it.⁷³

68 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 2.

69 Professor E Elliott, University of Sydney, *Committee Hansard*, Sydney, 13 April 2012, p. 2.

70 Warren Harvey, *Submission 41*, p. 5.

71 D Smith, Halls Creek Kimberley Language Resource Centre, *Committee Hansard*, Mimbi, 11 July 2012, p. 8.

72 Australian Children's Commissioners and Guardians, *Submission 62*, p. 6.

73 Dr D Reeve, Acting Director, Kimberley Population Health Unit, *Committee Hansard*, Broome, 12 July 2012, p. 15.

- 4.72 Professor Elliott acknowledges the difficulties that are compounded by distance, but believes that trained mobile teams are the best model for regional and remote areas:

It is very hard, as you know, to get people to come and work in these communities, and then it is hard to get them to stay. That is because these communities are very remote. We are suggesting that the best model, the most sustainable model, is one where all the professionals can work together, travel together and get to know the communities. Even if they are not there every day of the year, they can come back – so that there is continuity and there is support from the team, rather than individuals working in isolation [where] the paediatrician comes one day, the speech therapist the next week, the physio the following week, and they can never talk to each other. If they could all see a child together, get the assessment done, make a diagnosis and get the report done, it would be much more efficient, and it would be much cheaper for the government.⁷⁴

After the diagnosis

- 4.73 A diagnosis should be followed up with a management plan and access to specialist and allied health services and professionals that enable the implementation of the plan. However, the Committee received few details of existing management services.
- 4.74 Dr Charles Kilburn, from Royal Darwin Hospital, told the Committee that:
- It is a little bit of an empty diagnosis if you make a diagnosis of foetal alcohol syndrome disorder but you do not have any services to apply to those children. If there were increased recognition from which some funding for remedial therapy flowed, then I think that would drive the recognition of the condition and certainly help improve diagnosis and status of the condition.⁷⁵
- 4.75 The Telethon Institute and the Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders confirmed that there is little good evidence on the forms of management that are effective for

74 Professor E Elliott, University of Sydney, *Committee Hansard*, Mimbi, 11 July 2012, p. 8.

75 Dr C Kilburn, Chief Paediatrician, Royal Darwin Hospital, *Committee Hansard*, (Videoconference) Darwin, 21 June 2012, p. 8.

individuals with FASD, due to a lack of proper trials and evaluation studies of FASD therapies.⁷⁶

4.76 In contrast, the NRHA submitted that:

The most promising ways of helping people with FASD appear to be behavioural, environmental and relationship-driven interventions ... Building upon strengths and assets is proving to be a better approach than focusing solely on difficulties. Five evidence-based intervention strategies have been shown to have positive results in the United States and funding should be made available to provide such programs in Australia.⁷⁷

4.77 Legal Aid New South Wales and Aboriginal Legal Service (New South Wales/ Australian Capital Territory) claimed that:

... the solutions are fairly simple in a sense. They are not cheap, but they are simple. In modern disability sciences there are any number of well-proven, early intervention methodologies, disability support methodologies, that are not rocket science and they are fairly simple to institute, but they simply do not exist. We have seen pilot examples in Central Australia where people who have reached this critical stage of extremely challenging behaviours have had those behaviours modified and brought down to a manageable level where they can go and live good quality of lives with a moderate level of disability support.⁷⁸

4.78 Two Australian models of care, incorporating strategies for management, were brought to the attention of the Committee. The Lililwan Project in Fitzroy Valley developed 'Circle of Community Care', a model of care for 'a collaborative circle of community care really to support parents and carers and to coordinate the health, education and other needs of these children and their families'.⁷⁹

4.79 In Western Australia, the Child and Youth Health Network developed a state FASD model of care 'which sets out the key directions across the continuum from prevention through to management of FASD' that 'aligns to the national agenda'.⁸⁰ The state Department of Health is coordinating

76 Telethon Institute, *Submission 23*, p.11; Intergovernmental Committee on Drugs Working Party on Fetal Alcohol Spectrum Disorders, *Fetal Alcohol Spectrum Disorders: An Update*, 2009, p. 86.

77 NRHA, *Submission 40*, pp. 15-16.

78 J McKenzie, Chief Legal Officer, Aboriginal Legal Service, (New South Wales and the Australian Capital Territory) Ltd, *Committee Hansard*, Sydney, 13 April 2012, p. 22.

79 Professor E Elliott, University of Sydney, *Committee Hansard*, Canberra, 24 November 2011, p. 2.

80 B Whitworth, Senior Development Officer, WA Health, *Committee Hansard*, Perth, 10 July 2012, p. 6.

the whole-of-government, multi-sector approach to implementing the model.⁸¹ However, no additional funding has been allocated to the FASD model of care, which relies instead on funds drawn from other areas.⁸²

4.80 As discussed in the previous section, remote areas suffer from a shortage of health professionals and services, compromising access to ongoing care and management. The WA Model of Care takes into account the remote nature of many of its communities, which often lack health services, and recommended the following models of service delivery:

- Workforce training and development in regional centres to provide a local service. This should be prioritised according to level of need, ie according to established or estimated prevalence of FASD in local communities.
- Scheduled rural visits by metropolitan-based teams with the opportunity of assessing whole subpopulations within a short time period and providing education and support to local services. Involvement of the local health service providers in the visiting team's assessment process will enable building of local expertise.
- Telehealth models for individual assessment.⁸³

4.81 A number of organisations, including the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council, the Aboriginal Disability Justice Campaign, and the Northern Territory branch of the Public Health Association of Australia expressed concern that individuals with FASD living in remote areas would miss out on intervention and management therapies due to the paucity of health services in general.⁸⁴

4.82 For example, the First Peoples Disability Network stated that it 'is very unlikely that speech pathology could be provided intensively in regional and remote parts of the country because of a lack of availability'.⁸⁵

4.83 Dr Mutch, who spent a brief time in Tennant Creek in the Northern Territory, said that:

I was deeply moved and saddened by the evident need for more services to support and enable health, diagnosis and therapy for developmental needs including specifically meeting the requirements of FASD. Professionals outside of health told me

81 WA Health, Health Networks Branch (Child and Youth Health Network), *Submission 13*, p. 7.

82 Western Australian Legislative Assembly Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The invisible disability*, September 2012, p. iii.

83 NRHA, *Submission 40*, pp. 14–15.

84 Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council, *Submission 74*, p. 7; Aboriginal Disability Justice Campaign, *Submission 43*, p. 5; Public Health Association of Australia – NT Branch, *Submission 73*, p. 3.

85 First Peoples Disability Network, *Submission 75*, p. 4.

how they were providing basic health services to facilitate wellbeing and education attendance as no other capacity was available to meet these needs. They spoke of the evident cognitive difficulties manifest in the children and their concern with how few amenities they had to meet their diverse needs.⁸⁶

- 4.84 A submission from a number of allied health services in Fitzroy Valley outlined the needs for increased capacity and stronger linkages with the Kimberley Paediatrics and Child Health Team in response to the raft of FASD diagnoses and management plans arising out of the Lililwan Project.⁸⁷
- 4.85 The Aboriginal and Torres Strait Islander Social Justice Commissioner stated that :
- It is ... imperative that children with FASD – wherever they live in Australia – have equitable access to the services they need to optimise their health, development and educational outcomes.⁸⁸
- 4.86 This problem is not confined to remote communities. Dr Louise Martin noted that an appropriate increase in capacity and resources in Darwin is required to ensure that the therapeutic response can match any increase in diagnosis levels.⁸⁹ The capacity of allied health services and infrastructure in the Top End of the Northern Territory is already limited, with long waiting lists, meaning that children’s therapeutic needs often are not being met.⁹⁰ In Townsville, a foster carer told the Committee that she occasionally took children herself to private hospitals to avoid the lengthy public waiting lists.
- 4.87 FARE considers that there is much to be learned from other examples from the disability area and how governments have responded.⁹¹ The FARE submission outlined the changes in how Autism Spectrum Disorders (ASD) has been managed in Australia over the last few years. In 2007 a report from the Australian Advisory Board on ASD identified the following four areas that needed concerted national effort:

86 Dr R Mutch, *Submission 77*, p. 1.

87 Allied Health Services –The Lililwan Project, *Submission 88*, p. 5.

88 Aboriginal and Torres Strait Islander Social Justice Commissioner, *2010 Social Justice Report*, Australian Human Rights Commission, Sydney, 2011, p. 93.

89 Dr L Martin, Royal Darwin Hospital, *Committee Hansard*, Canberra (Videoconference), 21 June 2012, p. 5.

90 Paediatricians at Royal Darwin Hospital, *Submission 79*, p. 3.

91 M Thorn, Chief Executive Officer, Foundation for Alcohol Research and Education (FARE), *Committee Hansard*, Canberra, 31 May 2012, p. 3.

- access to timely and affordable diagnosis with a wait time of no longer than three months for diagnosis and assessment by multidisciplinary teams;
 - early intervention services to allow for better outcomes for children;
 - specific educational services to assist children to transition to mainstream schools; and
 - improved data collection to help future research into causes, diagnostic pathways, effective interventions and outcomes.⁹²
- 4.88 Of course, there are still difficulties accessing diagnoses, early intervention, and support for children with ASD.⁹³ As with ASD, access to diagnosis, early intervention, and specialised services for FASD are all areas which need further attention. However, FASD has not received the same attention, support or public recognition in Australia.⁹⁴
- 4.89 The next chapter discusses non-health sector management strategies and services for carers, the education sector and the criminal justice system.

Committee Comment

- 4.90 Australia's need for increased capacity to recognise, diagnose and manage the primary and secondary symptoms of FASD was a common refrain throughout the inquiry.
- 4.91 The Committee is convinced of the necessity and benefit of early intervention to improve the life outcomes of individuals born with FASD. Without a diagnosis, or with the wrong diagnosis, the treatment of individuals with FASD by their families, educators, physicians and society in general can inadvertently cause great damage and lead to severe secondary disabilities such as mental illness or substance abuse which may then lead on to incarceration. Early intervention is critical to unlocking a better future.
- 4.92 The Committee appreciates the difficulty of diagnosing conditions within the FASD spectrum. The Committee is concerned, however, that perceptions of stigma attached to FASD can obstruct accurate and timely diagnosis. The stigma of overlooking or ignoring the needs of individuals with FASD should be greater than any stigma linked to maternal alcohol consumption.

92 FARE, *Submission 36*, p. 8.

93 For example see, Western Australian Legislative Assembly Education and Health Standing Committee, *Foetal Alcohol Spectrum Disorder: The invisible disability*, September 2012, p. 67.

94 FARE, *Submission 36*, pp. 8-9.

- 4.93 In addition to a fear of stigmatising families, health professionals appear to have low levels of training and knowledge about FASD. The Committee is of the view that the capacity of health professionals to identify FASD must be improved, and that a national effort should be mounted to ensure uniformity across all states. All health professionals who deal with children should be educated on the prevalence, aetiology and clinical features of FASD, and on the appropriate diagnostic and management services for referral.
- 4.94 The Committee understands that FASD is very complex, and requires the expertise of a number of specialists to diagnose. This makes the introduction of a standard diagnostic and screening instrument even more imperative, so that the prevalence of FASD can be measured and monitored consistently across the country.
- 4.95 The Committee is encouraged that the Commonwealth Government commissioned an Australian diagnostic tool. The diagnostic tool is yet to be trialled and evaluated, so the Committee recommends that no more time is lost and the diagnostic tool released along with guidelines for its use.

Recommendation 15

- 4.96 **The Committee recommends that the Commonwealth Government expedite the rollout of the Fetal Alcohol Spectrum Disorder (FASD) diagnostic instrument and the development of a training and user manual. These should be available for use by 1 October 2013.**

Following the rollout, the Commonwealth Government should establish a mechanism to collect and monitor diagnostic data in order to assess the effectiveness of prevention strategies and patterns of FASD occurrence.

- 4.97 Use of the nationally-recognised diagnostic instrument would enable the establishment of diagnostic clinics or teams. At present, there are few options in Australia for people who suspect and are seeking a diagnosis of FASD. The Committee is saddened that some families had to consult doctor after doctor, or even travel overseas, in order to receive confirmation of a suspected FASD diagnosis.
- 4.98 However, the Committee acknowledges that a diagnosis of FASD would be empty without a viable management plan. The Committee commends the models of care created by the WA Government and the Lililwan Project community. These models seek to integrate the many practitioners

- necessary for a holistic approach to FASD prevention, diagnosis and management.
- 4.99 Unfortunately, just as the capacity of health professionals in Australia to recognise FASD is limited, so is their capacity to provide effective therapies and support services. This is evident in rural and remote areas that struggle to achieve adequate health services for other disabilities. The Committee recognises that studies into the efficacy of various management strategies need to be conducted to inform the establishment of therapeutic programs.
- 4.100 The Committee is of the view that a national diagnostic and management strategy should be established to overcome the obstacles discussed in this chapter. This strategy should take into account existing models and programs in Australia and best-practice examples from North America.
- 4.101 The Committee considers that the FASD Reference Group is best placed to develop this national strategy. The strategy should increase health professionals' awareness of FASD and the importance of early diagnosis and management. The Committee suggests that rigorous screening of pregnant women and children in high-risk groups be instituted in every state and territory to enable the earliest detection of FASD or other disabilities.
- 4.102 The strategy should identify the ideal diagnostic service models so that access to the national diagnostic and screening tool is available to all, regardless of geographic residence. There was strong evidence in the inquiry pointing to the benefits of mobile interdisciplinary teams, but the Committee is not qualified to comment on the most appropriate model.
- 4.103 Finally, the strategy should ensure that management services are properly researched and evaluated so that evidence-based recommendations can be made for individuals' management plans.

Recommendation 16

- 4.104 **The Committee recommends that the Commonwealth Government develop and implement a national Fetal Alcohol Spectrum Disorders (FASD) diagnostic and management services strategy.**

This strategy should be monitored and informed by the FASD Reference Group, and should establish capacity by 1 July 2014 for the following:

- **awareness amongst all general practitioners and child and maternal health professionals of the causation and clinical features of FASD and the importance of early diagnosis and intervention;**
- **establishment of a model for diagnostic services such that regional as well as metropolitan areas are properly serviced; and**
- **identification of effective methodologies of management including international best practice.**

