



**Legislative Assembly for the  
Australian Capital Territory**

Standing Committee on Health and  
Community Wellbeing

# **Review of ACT Health Programs — Children and young people and responses to Fetal Alcohol Spectrum Disorder (FASD)**

Legislative Assembly for the Australian Capital Territory  
Standing Committee on Health and Community Wellbeing

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Approved for publication

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Report 5  
10th Assembly  
April 2022



# About the committee

## Establishing resolution

The Assembly established the Standing Committee on Health and Community Wellbeing on 2 December 2020, amended on 11 February, 30 March, 22 April, 16 September, 9 November 2021, and 10 February 2022.

The Committee is responsible for the following areas:

- Health and health system
- Justice health
- Mental health
- Homelessness and housing services
- Prevention of domestic and family violence
- Families
- Community services

The full establishing resolution can be found [on the Committee's website](#).

## Committee members

Mr Johnathan Davis MLA, Chair

Mr James Milligan, Deputy Chair (from 6 April 2021)

Mrs Elizabeth Kikkert, Deputy Chair (from 9 December 2020 to 30 March 2021)

Mr Michael Petterson MLA

## Secretariat

Dr David Monk, Committee Secretary

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## About this inquiry

Under Standing Order 216, standing committees can self-initiate an inquiry into any subject area it is given responsibility for by the establishing resolution.

On 30 March 2021, the Standing Committee on Health and Community Wellbeing resolved to conduct an inquiry into programs in place in the ACT providing for children and young people to assess the adequacy, availability, and implementation of the following:

- a) identify and review all aspects of current screening and health assessment programs and processes in the ACT for hearing, vision, speech, motor-skill difficulties, and general health of children and young people;
- b) identify and review in particular all aspects of current preventative programs and associated programs for screening, diagnosis, assessment and treatment in the ACT for Fetal Alcohol Spectrum Disorder (FASD);
- c) identify and review current programs in the ACT providing services that address the support, treatment and assessment arising from diagnosis of anything requiring treatment in a) and b); and
- d) any other relevant matters arising during the Committee's inquiry.

As part of its inquiry, the Committee will also report on the implementation of the National FASD Strategic Action Plan 2018-2028 and the National Action Plan for the Health of Children and Young People 2020-2030 in the ACT.

The committee informed the Assembly of its intention to conduct this inquiry on 30 March 2021.

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# Acronyms

Acronym	Long form
2021 Senate Committee Report	Senate; Standing Committee on Community Affairs, <i>Effective Approaches to Prevention, Diagnosis and Support for FASD March 2021</i>
ACT	Australian Capital Territory
ACTCOSS	ACT Council of Social Service
ACTHD	ACT Health Directorate
AFI	Advocacy for Inclusion
AMA	Australian Medical Association
AOD	Alcohol and other drugs
ASD	Autism Spectrum Disorder
ATODA	Alcohol Tobacco and Other Drugs Association
AUGP	Academic Unit of General Practice
BMI	Body Mass Index
CDS	Child Development Service
CEO	Chief Executive Officer
CHN	Capital Health Network
CHS	Canberra Health Services
COAG	Council of Australian Governments
CPHB	Calvary Public Hospital Bruce
CSD	Community Services Directorate
CYPS	Child and Youth Protection Services
DIC	Drop-In-Clinics
DSAP	ACT Drug Strategy Action Plan 2018-2021
ECEI	Early Childhood Early Intervention
ENT	Ear, Nose, and Throat Clinic
FARE	Foundation for Alcohol Research and Education
FASD	Fetal Alcohol Spectrum Disorder
GET UP	Group Engaging The Under 25 Parents
GP	General Practitioner
HCCA	Health Care Consumers' Association
Hidden Harm Report	House of Representatives; Standing Committee on Social Policy and Legal Affairs, <i>The Hidden Harm: Inquiry into the prevention, diagnosis, and management of FASD</i>
IMPACT	Integrated Multi-agencies for Parents and Children Together Program

KHC	Kindergarten Health Check
LGBTIQ+	Lesbian, Gay, Bisexual, Transgender, Intersex, and Queer
MACH	Maternal and Child Health
MIEACT	Mental Illness Education ACT
MLA	Member of the Legislative Assembly
MOST	Moderated Online Social Therapy
National Action Plan	<i>National Action Plan for the Health of Children and Young People: 2020-30</i>
National FASD Plan	<i>National FASD Strategic Action Plan 2018-2028</i>
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NGO	Non-Governmental Organisations
NSW	New South Wales
OT	Occupational Therapist
PEDS	Parents Evaluation of Development Status
POPPY	Parents' Opportunity to Participate in Play with their Young
QEII	Tresillian Queen Elizabeth II Family Centre
QTON	Questions Taken on Notice
SHFPACT	Sexual Health and Family Planning ACT
STEPS	Adolescent Step Up/Step Down Supported Accommodation and Transitional Outreach Support
TwHSP	Territory-wide Health Services Plan
WYCCHP	Women Youth and Children, Community Health Programs
YAM Program	Youth Aware of Mental Health Program

# Recommendations

## Recommendation 1

The Committee recommends that the ACT Government include its implementation of the 2018-2028 FASD Strategic Action Plan and the 2020 National Action Plan for Health of Children and Young People in annual reports.

## Recommendation 2

The Committee recommends that the ACT Government improve early detection of disability in the ACT, including establishing these services for FASD.

## Recommendation 3

The Committee recommends that the ACT Government prioritise recruitment of paediatricians.

## Recommendation 4

The Committee recommends that GPs, paediatricians, and non-paediatrician specialists be upskilled to improve outcomes for young people accessing their services.

## Recommendation 5

The Committee recommends that the ACT Government establish measures to address shortcomings in FASD screening and diagnosis to determine the prevalence of FASD in the ACT.

## Recommendation 6

The Committee recommends that the ACT Government advocate for easier access to NDIS for people with FASD.

## Recommendation 7

The Committee recommends that the ACT Government implement strategies to increase awareness of FASD amongst health care workers, families and community.

## Recommendation 8

The Committee recommends that the ACT Government provide more resourcing to the AOD sector that would support them to conduct more community education and awareness campaigns.

## Recommendation 9

The Committee recommends that the ACT Government enables more flexibility in their contracts with the AOD sector to provide for AOD in ACT public schools, with particular focus on early secondary years.

## Recommendation 10

That Committee recommends that the ACT Government ensure continuity of health care for patients across jurisdictions and provide related support for their families.

### **Recommendation 11**

The Committee recommends that the ACT Government increase funding to community organisations who provide specialised services for young people and their families.

### **Recommendation 12**

The Committee recommends that the ACT Government provide increased access to affordable mental health support for children and young people in the ACT.

### **Recommendation 13**

The Committee recommends that the ACT Government employs more people with a disability across the ACT public service.

### **Recommendation 14**

The Committee recommends that the ACT review and improve the hospital and health care experience and processes for young people and their families, focusing on a family centred care model.

# 1. Conduct of the Inquiry

## Background

- 1.1. On Tuesday, 23 March 2021, the Standing Committee on Health and Community Wellbeing resolved to inquire into the matters in the Terms of Reference for this inquiry<sup>1</sup>.
- 1.2. On Tuesday, 30 March 2021, the Committee advised the ACT Legislative Assembly of its self-referred inquiry and its plan for the inquiry. The Committee advised the Assembly that it was inviting submissions on the inquiry and would report on the reference by the end of November 2021.
- 1.3. The Committee agreed to amend its Terms of Reference for the inquiry on Tuesday, 7 December 2021, and set a new reporting date of Friday, 8 April 2022.
- 1.4. The Committee received 11 submissions to the inquiry. These are listed in Appendix A.
- 1.5. The Committee held two public hearings on Tuesday, 28 September 2021 and Tuesday, 2 November 2021. Witnesses who appeared at these hearings are listed in Appendix B.
- 1.6. The Committee had six Questions Taken on Notice from the public hearing on Tuesday, 2 November 2021. These are listed in Appendix C.

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<sup>1</sup> Standing Committee on Health and Community Wellbeing, *Terms of Reference - Review of ACT health programs for children and young people*, [https://www.parliament.act.gov.au/\\_data/assets/pdf\\_file/0007/1766815/HCW-ToR-health-programs-for-children-and-young-people.pdf](https://www.parliament.act.gov.au/_data/assets/pdf_file/0007/1766815/HCW-ToR-health-programs-for-children-and-young-people.pdf), accessed 17 December 2021.

## 2. Areas covered by the inquiry

### Introduction

- 2.1. As noted earlier, this report is by way of a review (and something of a snapshot) of how ACT health agencies – both government and non-government – are managing the issues highlighted in the Terms of Reference of the inquiry.
- 2.2. In doing so, the Committee is aware that the two areas of health management under scrutiny are the subject of considerable structural programming and direction, mainly through two National Plans coordinated through the Commonwealth Department of Health.
- 2.3. This structural approach, which in the case of both areas of health administration and management, is a central point of reference for the Committee, for users, and for participants in these important areas.

### Child and youth health

- 2.4. The Committee conducted this inquiry as a review. The first section of this review was of programs identified as those administered by ACT health agencies and by other groups and agencies which provide health monitoring, screening, developmental support, mental and physical health programs and preventative plans and responses for children (ages 1 to 12) and youth (ages 12 to 18).
- 2.5. This area of health activity is now included in the National Action Plan for the Health of Children and Young People: 2020-2030 (the National Action Plan):

The National Action Plan builds on *Healthy, Safe and Thriving: National Strategic Framework for Child and Youth Health* and outlines Australia's national approach to improving health outcomes for all children and young people, particularly those at greatest risk of poor health.<sup>2</sup>

- 2.6. Through a life course approach, the National Action Plan recognises that there are a range of health needs, risks and influences experienced by children and young people at different stages of life and focuses on the importance of specific investments to maximise physical, mental and social health at every age.<sup>3</sup>
- 2.7. Following a consultative process and review of evidence, five priority areas have been identified to drive change and improve outcomes in order to ensure the health of Australia's children and young people:

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<sup>2</sup> Australian Government Department of Health, *National Action Plan for the Health of Children and Young People: 2020-2030*, <https://www1.health.gov.au/internet/main/publishing.nsf/Content/child-and-youth-action-plan>, accessed 3 December 2021.

<sup>3</sup> Australian Government Department of Health, *National Action Plan for the Health of Children and Young People: 2020-2030*, <https://www1.health.gov.au/internet/main/publishing.nsf/Content/child-and-youth-action-plan>, p 1, accessed 3 December 2021.

1. Improve health equity across populations;
  2. Empower parents and caregivers to maximise healthy development;
  3. Tackle mental health and risky behaviours;
  4. Address chronic conditions and preventive health; and
  5. Strengthen the workforce.<sup>4</sup>
- 2.8. The figure on the next page captures the National Action Plan’s overview, including guiding principles, priority areas and action, and operational enablers.

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<sup>4</sup> Australian Government Department of Health, *National Action Plan for the Health of Children and Young People: 2020-2030*, <https://www1.health.gov.au/internet/main/publishing.nsf/Content/child-and-youth-action-plan>, p 1, accessed 3 December 2021.

# Action plan overview

*Ensure that Australian children and young people, from all backgrounds and all walks of life, have the same opportunities to fulfil their potential, and are healthy, safe and thriving*

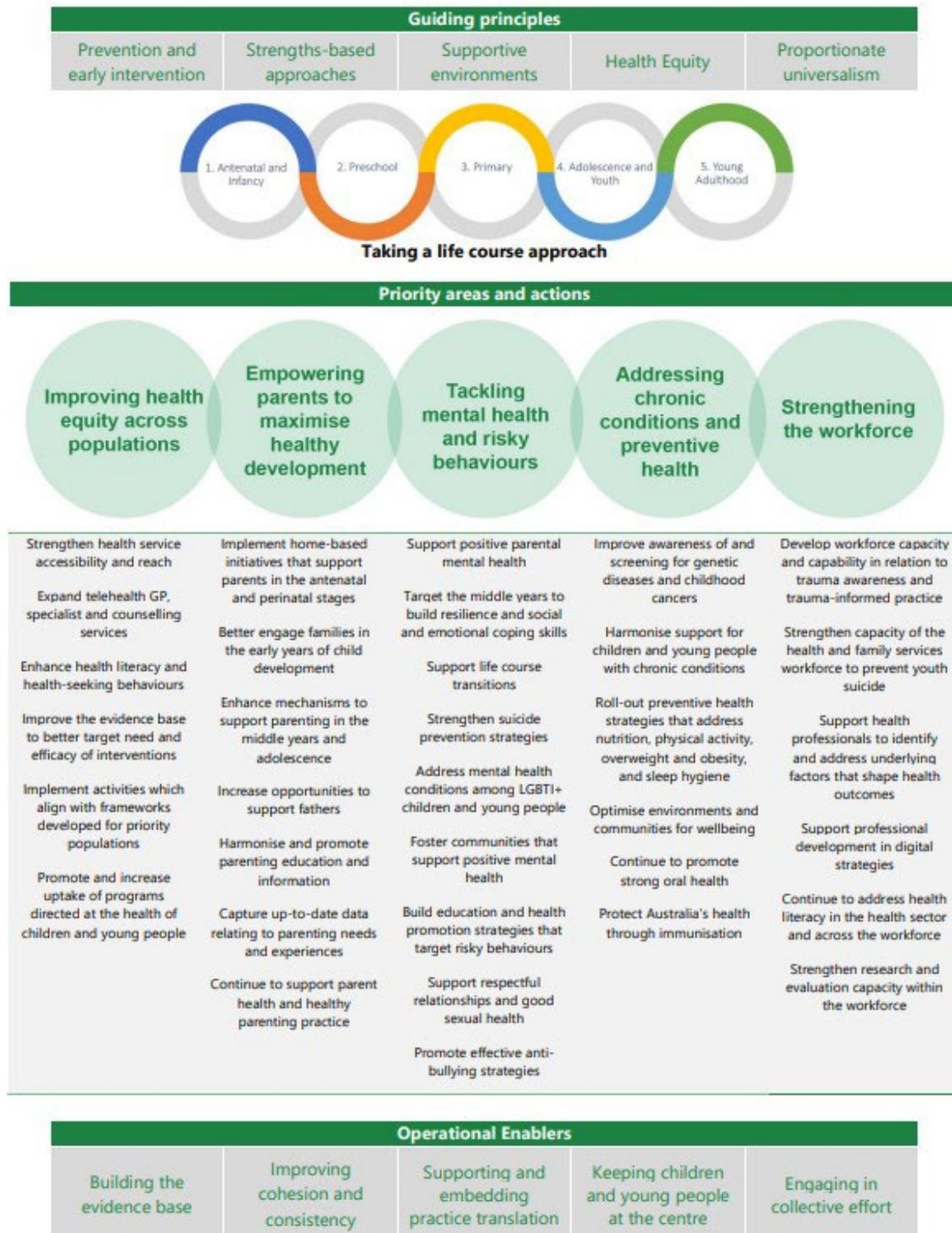


Figure 1: National Action Plan overview [Source: Australian Government Department of Health, 2019, *National Action Plan for the Health of Children and Young People: 2020-2030*, p 3.]

2.9. The rationale for the National Action Plan is stated as follows:

The need for a National Action Plan for children and young people reflects cumulative knowledge and evidence that what we do now matters for the future of our society. Despite an improving trend in population health outcomes in the last century, it acknowledges a need to tackle gaps and inequities in health outcomes for children and young people, and to address emerging challenges in certain domains of health and wellbeing. The National Action Plan manifests to focus and shape collaborative efforts from partners across the health sector and wider society, to address priorities and implement activities collectively more effectively. Action from everyone matters and continued action is needed.<sup>5</sup>

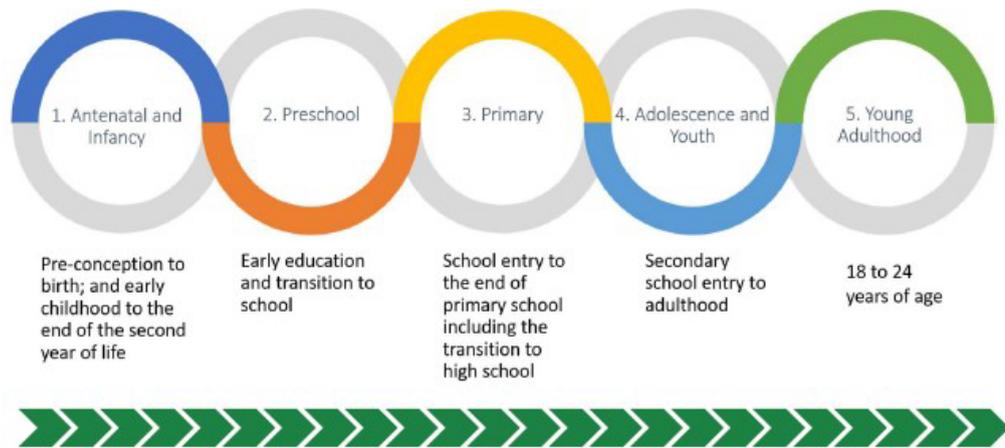
- 2.10. Early childhood in particular offers a crucial ‘window of opportunity’ for investment and early intervention, not only to prevent or reduce adverse outcomes but to maximise the life chances of children and young people so that they can thrive.<sup>6</sup>
- 2.11. Adolescence too represents a vital period for development, in which biological and psychosocial changes present a ‘window of vulnerability’ through which pathways can be set – positively or negatively – towards lifelong health outcomes.<sup>7</sup>
- 2.12. The figure on the next page shows the key life stages, risks, and intervention focus for children and young people.

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<sup>5</sup> Australian Government Department of Health, *National Action Plan for the Health of Children and Young People: 2020-2030*, <https://www1.health.gov.au/internet/main/publishing.nsf/Content/child-and-youth-action-plan>, p 3, accessed 8 December 2021.

<sup>6</sup> Australian Government Department of Health, *National Action Plan for the Health of Children and Young People: 2020-2030*, <https://www1.health.gov.au/internet/main/publishing.nsf/Content/child-and-youth-action-plan>, p 3, accessed 8 December 2021.

<sup>7</sup> Australian Government Department of Health, *National Action Plan for the Health of Children and Young People: 2020-2030*, <https://www1.health.gov.au/internet/main/publishing.nsf/Content/child-and-youth-action-plan>, p 3, accessed 8 December 2021.



Leading causes of burden of disease	Infant & congenital conditions are the dominant burden at this stage	Mental & substance use disorders Injuries Infectious diseases peak at this stage	Mental & substance use disorders increase substantially at this point Respiratory diseases peak Injuries Skin disorders emerge	Mental & substance use disorders persist Injuries emerge as an increased burden at this stage Respiratory diseases begin to decline as burden Skin disorders Musculoskeletal conditions emerge as greater burden	
Select health intervention focus points and pathways	Pre-conception and antenatal care Breastfeeding preparation & promotion Maternal alcohol use & smoking cessation Maternal mental health Parenting skill development Access to health & social care Nutrition	Parenting skill development Social & emotional wellbeing Nutrition Physical activity Obesity prevention Access to health & social care	Parenting skill development School-based nutrition Physical activity Obesity prevention School-based social & emotional learning Participation in sport & community activities	Parenting skill development School-based health & wellbeing Behavioural management Substance misuse prevention Sexual health Mental health promotion Suicide prevention Prevention of risky behaviours	Access to adult health services Young parenthood Sexual health Mental health promotion Suicide prevention Substance misuse prevention Prevention of risky behaviours Civic participation Relationship support

Figure 2: Life course approach for the key life stages, risks, and intervention focus for children and young people [Source: Australian Government Department of Health, 2019, *National Action Plan for the Health of Children and Young People: 2020-2030*, p 5.]

- 2.13. Despite some significant achievements improving health outcomes for children and young people, there are areas which lag behind and growing challenges to address. Progress has been made in areas such as infant mortality, substance use, injury deaths, and the provision of antenatal care — however, Australian children and young people are now more likely than ever before to be overweight or obese, are less likely to be predominantly or exclusively breastfed at six months, and increasingly face homelessness.<sup>8</sup>
- 2.14. A growing concern is the mental health of our children and young people. The *2017 Youth Mental Health Report* (a collaborative five-year report between Mission Australia and the Black Dog Institute, which presented five years of mental health data collected from young people across Australia) found that one in four young people are at risk of serious mental

<sup>8</sup> Australian Research Alliance for Children and Youth, *Report Card 2018: The Wellbeing of Young Australians*, March 2018, p 16.

illness, with risk increasing as adolescents age and more prominent among Indigenous Australians and young women. Furthermore, the number of deaths by suicide of young Australians in 2015 was the highest it has been in ten years.<sup>9</sup>

- 2.15. Furthermore, in their submission to the inquiry, Ms Jodie Griffiths-Cook, Public Advocate and Children and Young People Commissioner for the ACT Human Rights Commission, wrote that:

...Canberra teens consistently report some of the highest rates of psychological distress in the country, with nearly half of all 17-year-olds surveyed experiencing it. Support systems are often over-subscribed and have long wait times and many young people are not accessing timely support. *The Review of Children and Young People in the ACT* by the Office for Mental Health and Wellbeing found that the main obstacle to accessing treatment identified by survey respondents was the long wait times.<sup>10</sup>

## Fetal Alcohol Spectrum Disorder (FASD)

- 2.16. The second aspect of the Committee's review of ACT health services addresses the current ACT programs directed at all aspects of Fetal Alcohol Spectrum Disorder (FASD).
- 2.17. FASD is a diagnostic term used to describe a range of birth defects and neurodevelopmental impairments that may occur as a result of exposing the fetus to alcohol during pregnancy.<sup>11</sup> FASD is a lifelong condition with no cure, and the harm done by alcohol may not be evident at birth, but the central nervous system damage which the child is born with is irreversible and permanent, and current treatment options are predominantly supportive.<sup>12</sup>
- 2.18. This working definition and description is universally accepted and was used as the basis for a recent review of FASD responses in Australia by a major Senate inquiry, which was the Senate Standing Committee on Community Affairs' report, *Effective Approaches for prevention, diagnosis, and support for Fetal Alcohol Spectrum Disorder* (referred to in this report as the 2021 Senate Committee Report).
- 2.19. The following paragraphs from Chapter 1 of the 2021 Senate Committee Report describes the unique pervasive problem FASD presents:

FASD remains largely invisible and under-recognised in Australia. However, it is one of the leading causes of preventable birth defects and intellectual disability. Whilst there are no reliable figures on the prevalence of FASD in Australia, experts

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<sup>9</sup> Mission Australia and Black Dog Institute, *Youth Mental Health Report: Youth Survey 2012-2016*, [https://blackdoginstitute.org.au/docs/default-source/research/evidence-and-policy-section/2017-youth-mental-health-report\\_mission-australia-and-black-dog-institute.pdf?sfvrsn=6](https://blackdoginstitute.org.au/docs/default-source/research/evidence-and-policy-section/2017-youth-mental-health-report_mission-australia-and-black-dog-institute.pdf?sfvrsn=6) (accessed 8 December 2021).

<sup>10</sup> Ms Jodie Griffiths-Cook, Public Advocate and Children and Young People Commissioner, ACT Human Rights Commission, *Submission 4*, p 2.

<sup>11</sup> National Health and Medical Research Council, *Australian guidelines to reduce health risks from drinking alcohol*, 2020, p 50.

<sup>12</sup> Senate Standing Committee on Community Affairs, Commonwealth of Australia, *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder*, March 2021, p 1.

estimate that it affects up to five per cent of the population, and that potentially between two and nine percent of babies are born with FASD each year.

FASD is not confined to a particular community or demographic; it is a disorder that crosses socio-economic, cultural and education boundaries. However certain groups are more likely to be vulnerable to FASD due to patterns of alcohol consumption. Despite national guidelines recommending total abstinence of alcohol during pregnancy, the risks are still not well understood by the community, and amongst health professionals. In fact, Australia has one of the highest rates of prenatal alcohol exposure in the world.

Obtaining a FASD diagnosis is notoriously difficult, and access to diagnostic and treatment services are limited in Australia, particularly in rural and remote areas. Failure to identify children at risk and to diagnose FASD means that many individuals do not receive recognition or support for their impairments through the health, education and justice systems. People with FASD experience lifelong challenges, including learning difficulties and disrupted education, mental illness and drug and alcohol problems. The average life expectancy for a child with FASD is 34 years. Significantly, children with FASD are over-represented in the child protection and youth justice systems.<sup>13</sup>

## Parliamentary examinations and reports on FASD

### 2012 Hidden Harm Report

- 2.20. In 2012, the House of Representatives Standing Committee on Social Policy and Legal Affairs tabled a report titled, *FASD: The Hidden Harm – Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders* (referred to in this report as the Hidden Harm Report).
- 2.21. The Committee was asked to inquire into and report on developing a national approach to the prevention, intervention and management of FASD in Australia, with particular reference to prevention strategies, intervention needs, and management issues.
- 2.22. The Hidden Harm Report concluded that the Australian Government needed to lead the way in recognising FASD as a legitimate and serious disability with national dimension, and that a cohesive national approach was necessary. It contained 19 recommendations, with clear timeframes, focusing on national-level policy and coordination efforts.
- 2.23. Some of the recommendations included:
- implement a National Plan of Action and a FASD Reference Group;
  - improve data collection on alcohol consumption by health professionals during pregnancy or at the time of birth;

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<sup>13</sup> Senate Standing Committee on Community Affairs, Commonwealth of Australia, *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder*, March 2021, pp 2-3.

- develop a FASD diagnostic tool and training manual;
- implement awareness campaigns for the general public and specific to youth and Indigenous communities;
- implement health advisory labels on pregnancy and ovulation testing kits and on alcoholic beverages;
- commission an independent study into alcohol marketing, pricing and availability; and
- recognise FASD on the List of Recognised Disabilities.<sup>14</sup>

## 2021 Senate Committee Report

- 2.24. As noted earlier, the 2021 Senate Committee Report detailed its review of all aspects of FASD responses in Australian health programs and proposed a number of new courses to be followed in combatting FASD. The report contained 32 recommendations, including:
- develop a broader strategy and budget for a national public education campaign;
  - implement marketing, pricing and taxation reforms as set out in the National Alcohol Strategy 2019–2028;
  - undertake a national audit of current FASD diagnostic services and funding;
  - for the Department of Health to allocate specific funding aimed at supporting First Nations community-led projects to prevent and manage FASD; and
  - recognise FASD on the List of Recognised Disabilities.<sup>15</sup>
- 2.25. In addition to its own observations and findings on the implementation of programs and plans directed at FASD nationally, the 2021 Senate Committee Report noted a number of matters in a section titled ‘Reflecting on the past decade’ (being the period since the Hidden Harm Report published in 2012).
- 2.26. These reflections included:

The investment in research and innovative programs in the past decade has seen Australia move to the forefront in international efforts for FASD prevention, diagnosis and support. The first prevalence study in Australia was undertaken in Fitzroy Crossing, WA, and has resulted in a world class community led Marulu strategy and programs.

Despite this progress, there is still a limited awareness of FASD in the community and mixed messages about drinking during pregnancy in the general population and from health professionals. A lack of FASD prevalence data continues to undermine policy efforts and the limited diagnostic and support services available

<sup>14</sup> House of Representatives Standing Committee on Social Policy and Legal Affairs, Parliament of Australia, *FASD: The Hidden Harm – Inquiry into the prevention, diagnosis and management of Fetal Alcohol Spectrum Disorders*, November 2012, pp xvii-xxii.

<sup>15</sup> Senate Standing Committee on Community Affairs, Commonwealth of Australia, *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder*, March 2021, pp xix-xxiii.

across the country are struggling to keep up with demand. There are also growing concerns about the prevalence of FASD in the child protection and justice systems, and the potentially immense social and economic cost of FASD for the community more broadly.

Since the committee started its inquiry in November 2019, several significant FASD policy and budget announcements have been made, relevant to the inquiry's terms of reference. This includes the *National Alcohol Strategy* announced in November 2019, and additional Australian Government funding with a combined value of \$49 million for FASD diagnostic and treatment services, and for a national education campaign.<sup>16</sup>

## National FASD Strategic Action Plan 2018-2028

### 2.27. The 2021 Senate Committee Report noted the course of the development and implementation of a National FASD plan:

In November 2018, the National Fetal Alcohol Spectrum Disorder (FASD) Strategic action plan 2018–2028 (National FASD Plan) was launched as a sub-strategy of the National Alcohol Strategy. The plan was initiated in response to a review of the FASD action plan 2013–14 to 2016–17 by a roundtable of key FASD stakeholders and government agencies in December 2016.

The plan has received \$7.2 million in funding over four years to support prevention, diagnosis, support and management of FASD in Australia. The plan, which is not solely the responsibility of government bodies, is overseen by the Ministerial Drug and Alcohol Forum and supported by the National Drug Strategy Committee, which includes a FASD Advisory Group established to monitor implementation of the plan.

Funding under this plan is intended for several existing FASD initiatives including the national FASD case register, FASD Hub, Women Want to Know and Pregnant Pause programs. Funding will also be provided for other awareness raising and education activities and resources, including in the education and justice sectors, and will fund a review and update of the FASD diagnostic tool.

On 9 September 2020, the Minister for Health announced a further \$24 million under the National FASD Plan for FASD diagnostic and support services to improve wait times and support.<sup>17</sup>

### 2.28. The statement of content and intent on the National FASD Plan sets out goals and operational elements:

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<sup>16</sup> Senate Standing Committee on Community Affairs, Commonwealth of Australia, *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder*, March 2021, pp 10-11.

<sup>17</sup> Senate Standing Committee on Community Affairs, Commonwealth of Australia, *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder*, March 2021, p 8.

**Purpose:** The National FASD Strategic Action Plan 2018-2028 has been developed to provide a clear pathway of priorities and opportunities to improve the prevention, diagnosis, support and management of FASD in Australia. It builds on the significant foundational work and investment over recent years made by governments, non-government organisations, family advocates, researchers and clinicians, individual champions and communities who have raised awareness and supported individuals and their families living with FASD.

**Aim:** The National FASD Plan aims to reduce the prevalence of FASD and the impact it has on individuals, families, carers and communities. It identifies a series of priorities and opportunities to inform future approaches by governments, service providers and communities over the next decade.<sup>18</sup>

- 2.29. The implementation of the National FASD Plan should “establish and strengthen partnerships with families and carers, and the organisations that support them, so that the extent and nature of the collateral impact of harms of FASD is considered and minimised.”<sup>19</sup>

## Committee approach to the National Plans

- 2.30. As noted at the commencement of this report, the Committee is aware of the two major national health plans which have an overarching role in determining the ACT strategies and direction of Territory health programs in those areas of public health. As such, these plans directly impact the health of children and young people in the ACT. The Committee is of the view that their implementation should be included in the annual reporting process as a mechanism for review by the Legislative Assembly of the ACT.

### Recommendation 1

The Committee recommends that the ACT Government include its implementation of the 2018-2028 FASD Strategic Action Plan and the 2020 National Action Plan for Health of Children and Young People in annual reports.

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<sup>18</sup> Department of Health, *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028*, November 2018, p 3.

<sup>19</sup> Department of Health, *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018-2028*, November 2018, p 4.

### 3. Review of ACT Children and Youth Health programs

#### Screening and diagnosis

- 3.1. All the evidence before the Committee agreed that early intervention is essential in ensuring good health outcomes for children.<sup>20</sup> Delays in diagnosis and treatment can be highly detrimental to the patient, sometimes resulting in lifelong disability.<sup>21</sup>
- 3.2. In the ACT, screening for health problems starts with antenatal screening.<sup>22</sup> The Maternal and Child Health service provides development checks at key points during a child's first four years, and 85% of children are assessed through the Kindergarten Health Check in their first formal year of school.<sup>23</sup> When a potential health problem is identified, a referral is generally made to a GP or a specialist for diagnosis.
- 3.3. The Health Care Consumers Association of the ACT (the HCCA), stated that in terms of deficiencies within paediatrics in the ACT, 'delays in diagnosis were probably the ones that had the starkest issues'.<sup>24</sup> They highlighted the lack of specialists available to diagnose unusual or rare conditions such as genetic disorders.<sup>25</sup> According to the ACT Council of Social Service (ACTCOSS), children waiting for an autism spectrum disorder diagnosis can wait 6 to 12 months before seeing a psychologist.<sup>26</sup> Some specialist diagnostic services are not available at all in the ACT, such as for FASD.<sup>27</sup> For families forced to look interstate for services, this incurs a huge burden of cost and time, as well as risks to the integrity of their child's health care due insufficient communication between services, which will be discussed later.
- 3.4. Advocacy for Inclusion described the ways in which children and young people with a disability are at higher risk of coming into contact with the youth justice system or the emergency services, instead of receiving appropriate medical, due to missed opportunities for health screening.<sup>28</sup> They explained that these children can spend a lot of time interacting with people such as teachers, youth workers, or mainstream health professionals. However their disability needs remain unmet due to lack of awareness and education of the presentation of development delays, or other disabilities.<sup>29</sup>
- 3.5. The lack of specialist services available in the ACT to diagnose health problems in children leads to poorer outcomes for children and their families. Children with disabilities in

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<sup>20</sup> ACT Government, *Submission 1*, p [2].

<sup>21</sup> Dr Tito Wheatland, Hansard Proof Transcript, 28 September 2021, p 8.

<sup>22</sup> ACT Government, *Submission 1*, p [2].

<sup>23</sup> ACT Government, *Submission 1*, p [2] and [12]. Other services in the ACT provide screening for health issues such as hearing loss or neuromuscular disorders, see appendix D.

<sup>24</sup> Dr Tito Wheatland, *Committee Hansard*, 28 September 2021, p 7.

<sup>25</sup> Dr Tito Wheatland, *Committee Hansard*, 28 September 2021, p 8.

<sup>26</sup> ATCOSS, *Submission 9*, p 8.

<sup>27</sup> Foundation for Alcohol Research and Education, *Submission 10*, p [6].

<sup>28</sup> Ms Stacy Rheese, *Committee Hansard*, 28 September 2021, p 4.

<sup>29</sup> Ms Stacy Rheese, *Committee Hansard*, 28 September 2021, p 4.

particular are put at risk of disengagement at school and of becoming involved with the justice system if they are not properly identified and adequately supported from a young age.

### **Recommendation 2**

The Committee recommends that the ACT Government improve early detection of disability in the ACT, including establishing these services for FASD.

- 3.6. During the hearing on 2 November 2021, the Minister for Health spoke about the lack of paediatric services which led to families seeking interstate care:

I think we have acknowledged, as a government, that paediatric services are an area where we do need more capacity, and part of the challenge that we face at the moment is a recruitment challenge. We also face challenges across both the public and private systems in terms of the availability of paediatric care.<sup>30</sup>

- 3.7. Associate Professor Boon Lim, Acting Executive Director, Women, Youth and Children at Canberra Health Services, elaborated on the positions which the ACT Government is trying to fill:

We are currently working on the position descriptions for an extra two specialist paediatricians, general paediatricians, and a 0.5 FTE position for paediatric oncology and diabetes specialist as well. That will certainly help to bolster the number of specialists available in the ACT.

Our challenge has been trying to recruit a clinical director for paediatrics to provide leadership for the service. We are now in the process of looking at engaging a headhunting agency to try to cast the net wider to try to get a clinical director. We have been able to, until now, appoint specialists. It is really just to appoint a clinical director that has been our challenge.<sup>31</sup>

- 3.8. As discussed above, the shortage of paediatric services in the ACT is leading to long wait times for diagnosis and treatment of health conditions in children and young people.

### **Recommendation 3**

The Committee recommends that the ACT Government prioritise recruitment of paediatricians.

- 3.9. As well as a shortage in the quantity of paediatricians in the ACT, families report deficiencies in the quality of the service they receive for their children.<sup>32</sup> Families of

<sup>30</sup> Ms Rachel Stephen-Smith, Minister for Health, *Committee Hansard*, 2 November 2021, p 26.

<sup>31</sup> Associate Professor Boon Lim, Acting Executive Director, Women, Youth and Children, Canberra Health Services, *Committee Hansard*, 2 November 2021, p 27.

<sup>32</sup> Health Care Consumers Association ACT, *Submission 3*, p 4. Advocacy for Inclusion, *Submission 7*, p 6.

children with health conditions tend to spend more time with health practitioners, however this does not always translate to better outcomes.

- 3.10. The HCCA undertook a research project in 2020 to look at the experience of children and their families in accessing health care, and they noted that GPs were rarely useful to families as a central point of care:

GPs, who should be central to the coordination of a child's care in Canberra, were notably absent from the experiences of the people interviewed for the project. Where they did feature it was usually in a negative light as a barrier to diagnosis. They were noted for not listening to the parent's concerns or ordering diagnostic tests that were incorrect e.g. a blood test for paediatric brain cancer.<sup>33</sup>

- 3.11. The research project also revealed that children were often seen by non-paediatric specialists, who may or may not have the skills appropriate to diagnose and treat children.<sup>34</sup> A similar problem was reported by Advocacy for Inclusion. In their submission, they reported that children with a disability are often seen by health professionals who lack disability awareness and disability-related skills, which can lead to the following issues:

- poor communication with patients;
- lack of flexibility to accommodate the needs of the patient;
- difficulties in examination;
- difficulties in implementing management plans;
- misdiagnosis;
- diagnostic overshadowing<sup>35</sup>; and
- the appearance of 'tokenistic' disability awareness with little to no implementation of the relevant practices.<sup>36</sup>

- 3.12. The Committee notes that inappropriate health services can result in devastating effects for the patient, as per an example given by Dr Tito Wheatland:

The symptoms of juvenile arthritis are very spasmodic. It will come, they [the child] will be really sick for a few days and then they will get better and then they go to the GP. The mum and dad say, "These are the symptoms," and unless the GP has actually had much to do with juvenile arthritis, they might put it down to stomach upsets, flu or whatever. But if they do not pick it up early enough, the child can go blind, so this is one of those things where there is not a lot of wriggle room.<sup>37</sup>

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<sup>33</sup> Health Care Consumers Association ACT, *Submission 3*, p 4.

<sup>34</sup> Health Care Consumers Association ACT, *Submission 3*, p 4.

<sup>35</sup> Diagnostic overshadowing: when health complaints are incorrectly assumed to relate to the patient's disability.

<sup>36</sup> Advocacy for Inclusion, *Submission 7*, p 6.

<sup>37</sup> Dr Tito Wheatland, *Committee Hansard*, 28 September 2021, p 8.

- 3.13. The Committee believes that upskilling health professionals in the ACT is an effective way to utilise the staff resources that are currently available. If health professionals across the board were to have more training and experience in the presentation of health conditions in children and young people, they could diagnose and treat their patients quicker and more accurately or refer the patient to a more appropriate service.

#### Recommendation 4

The Committee recommends that GPs, paediatricians, and non-paediatrician specialists be upskilled to improve outcomes for young people accessing their services.

## FASD services

- 3.14. It is estimated that between two to nine percent of babies in Australia are born with FASD<sup>38</sup>, however the exact prevalence of the disorder remains unknown. In 2012, the Hidden Harm report recommended that the Commonwealth Government ‘establish a mechanism to collect and monitor diagnostic data’ of FASD,<sup>39</sup> however nearly a decade later, the 2021 Senate Committee Report noted that the data remains unreliable.<sup>40</sup>
- 3.15. The Foundation for Alcohol Research and Education (the Foundation) lists ‘lack of standardised data collection and monitoring’ as a key factor contributing to high rates of prenatal alcohol abuse.<sup>41</sup> During a hearing with the Committee, Ms Caterina Giorgi, the Foundation’s Chief Executive Officer, explained the difficulties in accurately determining FASD rates:

We need a better system for collecting data. There was a recommendation that came out of the national strategy to have a look at the prevalence study. The Australian government is looking at how that would be done. It is difficult for a range of reasons. One is that we do not routinely assess prenatal alcohol consumption. Another is that, when it comes to diagnosing FASD, if there is not a lot of diagnostic clinics, then there is not a lot of diagnosis that is happening.<sup>42</sup>

- 3.16. More than one submission pointed to the likelihood of high prevalence of children with FASD in the youth criminal justice system.<sup>43</sup> ACTCOSS noted in their submission that there are currently no screening mechanisms in place to record this information and allocate the appropriate therapeutic resources which may aid in preventing recidivism:

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<sup>38</sup> Foundation for Alcohol Research and Education, *Submission 10*, p 3.

<sup>39</sup> Hidden Harm p xxi.

<sup>40</sup> Senate Standing Committee on Community Affairs, Commonwealth of Australia, *Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder*, March 2021, p 34.

<sup>41</sup> Foundation for Alcohol Research and Education, *Submission 10*, p 3.

<sup>42</sup> Ms Caterina Giorgi, Chief Executive Officer, Foundation for Alcohol Research and Education, *Committee Hansard*, 28 September 2021, p 17.

<sup>43</sup> ACTCOSS, *Submission 9*, p 11; Foundation for Alcohol Research and Education, *Submission 10*, p 6.

Enhanced health screening for Bimberi youth with disability and the collection of related data would greatly assist in identifying what health factors may be better diagnosed early and responded to therapeutically rather than through the criminal justice system.<sup>44</sup>

- 3.17. As discussed in paragraphs 3.1 to 3.5, the insufficient screening and diagnosis services for disability amongst children and young people has significant repercussions for their future. The earlier a child receives a diagnosis for FASD, the early they can receive appropriate treatment, and the better their future outcomes.<sup>45</sup> Furthermore, accurate data on the prevalence of FASD would allow for targeted prevention strategies, potentially aimed at demographics most vulnerable to this type of alcohol harm.

### Recommendation 5

The Committee recommends that the ACT Government establish measures to address shortcomings in FASD screening and diagnosis to determine the prevalence of FASD in the ACT.

- 3.18. Through the inquiry, the Committee heard concerns about barriers to accessing the National Disability Insurance Scheme (the NDIS) for people with FASD. Only one in 10 people with a disability reportedly are granted NDIS funding, with Advocacy for Inclusion claiming confusion in eligibility requirements under NDIS criteria and recognition of FASD. The agency additionally submitted concerns that a legislative review of NDIS may also open further questions on eligibility.<sup>46</sup> The Foundation for Alcohol Research & Education explained that the process can be especially difficult when it comes to FASD:

NDIS support for people with FASD is possible, but the process is complex and fraught with barriers in relation to language and the burden of proof for functional impairments. Due to this difficulty many people with FASD do not gain NDIS support.

Another challenge with FASD and the NDIS is that there is a high prevalence of FASD in people detained in the criminal justice system, including children, who are excluded from the NDIS. The exclusion of people in prison who have a cognitive disability from the NDIS represents a substantial barrier to people with cognitive and mental health impairments getting adequate support, care and protection for their disability-related complex support needs.<sup>47</sup>

- 3.19. If a request for NDIS funding is denied, families may find themselves facing substantial out-of-pocket costs to access support services for their children, which disadvantages and potentially excludes families in lower socio-economic groups.<sup>48</sup> The ACT Government

<sup>44</sup> ACTCOSS, *Submission 9*, p 11.

<sup>45</sup> Ms Caterina Giorgi, Chief Executive Officer, Foundation for Alcohol Research and Education, *Committee Hansard*, 28 September 2021, p 15.

<sup>46</sup> Advocacy for Inclusion, *Submission 7*, p 5.

<sup>47</sup> Foundation for Alcohol Research and Education, *Submission 10*, pp 5-6.

<sup>48</sup> Advocacy for Inclusion, *Submission 7*, p 5.

submission confirmed that the ACT Government does not provide funding for on-going support services for children with FASD who are not eligible for NDIS.<sup>49</sup>

- 3.20. Another carer of a child with FASD spoke of the difference NDIS funding has made to their child, and of their concern should the funding be cut:

My daughter has had (since the introduction of NDIS) a support package which we have been using to support her development, through speech, physiotherapy, psychology and an inclusion support specialist. These supports have been extremely helpful ...

We are very concerned that we will lose all supports for her – we will be able to supply limited supports due to the massive increase in therapist costs with the introduction of NDIS and the inability to get a therapist and pay privately – they ONLY accept NDIS participants, we are EXTREMELY concerned for her future.<sup>50</sup>

- 3.21. At the time of writing their submissions, individuals and organisations were concerned about potential legislative changes which appeared to ‘tighten the set of conditions which constitute development delay, including removing ones attributable to a physical and mental impairment.’<sup>51</sup> The Committee notes that not all the proposed changes from this time came to pass,<sup>52</sup> however there have been media reports of funding cuts for individuals with cognitive impairments.<sup>53</sup>
- 3.22. As stated by the National FASD Plan, ‘increasing access to appropriate, evidence-based diagnosis and support services is a crucial strategy for improving care and support for people with FASD and their families.’<sup>54</sup> The difficulties faced by families of children with FASD in accessing care through the NDIS severely limits their abilities to support their children.

## Recommendation 6

The Committee recommends that the ACT Government advocate for easier access to NDIS for people with FASD.

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<sup>49</sup> ACT Government, *Submission 1*, p 5.

<sup>50</sup> Katherine O’Sullivan, *Submission 2*, p 1.

<sup>51</sup> ACTCOSS, *Submission 9*, p 9.

<sup>52</sup> Nas Campannella, Leonie Thorne and Celina Edmonds, ‘NDIS Minister says independent assessments model is ‘dead’, in a win for disability advocates’, ABC News, 9 July 2021, <https://www.abc.net.au/news/2021-07-09/ndis-disability-independent-assessments-model-dead-after-meeting/100277324>, accessed 17 March 2022.

<sup>53</sup> Luke Henriques-Gomes, ‘“Wildly unreasonable”: agency slashes mother’s NDIS funding and then her daughter’s’, ABC News, 24 February 2022, <https://www.theguardian.com/australia-news/2022/feb/24/wildly-unreasonable-agency-slashes-mothers-ndis-funding-and-then-her-daughters>, accessed 17 March 2022; Hilary Harper, ‘The NDIS and determining value for money’, Life Matters, ABC National Radio, 17 February 2022, <https://www.abc.net.au/radionational/programs/lifematters/the-ndis-and-determining-value-for-money/13757060>, accessed 17 March 2022.

<sup>54</sup> National Plan p 24.

3.23. The Alcohol Tobacco and Other Drug Association ACT (ATODA) lists three reasons that a pregnant woman might consume alcohol while pregnant:

- they do not know that they are pregnant;
- they do not know about the risks that alcohol poses to their unborn baby; or
- they have an alcohol dependency and struggle with abstaining.<sup>55</sup>

3.24. These factors are compounded by a lack of awareness of FASD amongst healthcare workers. This can include lack of awareness of how to suitably talk about it with their patients, ATODA explained:

Diagnosing FASD is not at all straightforward and involves a high degree of clinical judgement. It is also probably under diagnosed, in part because health professionals are not looking for it and in part because they may be reluctant to bring up a topic that is seen as stigmatising and uncomfortable.<sup>56</sup>

3.25. Although doctors question expectant mothers on their alcohol consumption during routine antenatal check-ups, ATODA has heard anecdotal reports of women lying about their drinking, possibly due to shame, or because they are afraid that they may lose custody of their baby.<sup>57</sup> As ATODA said in their submission, 'a patient indicating that they do not drink to a health professional might end the discussion about alcohol consumption, meaning that these women are not informed of the dangers.'<sup>58</sup> On such an occasion a patient with alcohol dependency would also not receive the information and support they need to abstain from drinking during pregnancy.

3.26. The Foundation for Alcohol Research and Education highlighted concerning data that one in three women between 18 and 45 did not know that alcohol use in pregnancy could cause adverse impacts, and that many women who were mothers or expectant mothers did not know that even moderate alcohol consumption could be dangerous.<sup>59</sup>

3.27. Expectant fathers do not always know about the risks of FASD either and in their ignorance can sometimes pressure their partners to drink.<sup>60</sup> Awareness amongst families, friends, and community is important for them to support pregnant women to stop drinking.<sup>61</sup>

3.28. For women to abstain from drinking during pregnancy or when they are trying to become pregnant, it is important that they receive the right advice from the healthcare system, and support from their families and communities, especially their partners.<sup>62</sup>

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<sup>55</sup> Dr Devan Bowles, Chief Executive Officer, Alcohol Tobacco and Other Drug Association ACT, *Committee Hansard*, p 12.

<sup>56</sup> Dr Devan Bowles, *Committee Hansard*, p 10.

<sup>57</sup> ATODA, *Submission 5*, p 1.

<sup>58</sup> ATODA, *Submission 5*, p 1.

<sup>59</sup> Foundation for Alcohol Research and Education, *Submission 10*, p 5.

<sup>60</sup> Foundation for Alcohol Research and Education, *Submission 10*, p 5.

<sup>61</sup> ATODA, *Submission 5*, p 1.

<sup>62</sup> ATODA, *Submission 5*, p 1

### Recommendation 7

The Committee recommends that the ACT Government implement strategies to increase awareness of FASD amongst health care workers, families and community.

- 3.29. As pointed out by ATODA, high alcohol consumption in society at large correlates with high levels of alcohol levels amongst pregnant women.<sup>63</sup> Therefore, if overall alcohol consumption is reduced, pregnant women are also less likely to be drinking when pregnant or when trying to become pregnant.
- 3.30. ATODA advised that funding the alcohol and other drug (AOD) sector to reduce drinking rates can result in a positive return on investment, by diverting people from the health and emergency services, and the justice system, which they might have otherwise been involved with due to excessive drinking.<sup>64</sup>
- 3.31. They also advised that pregnant women who seek help from AOD services are prioritised for treatment, which is beneficial for them and their unborn children, but does put strain on an already underfunded sector.<sup>65</sup> More funding to the AOD sector could help reduce stigma and increase awareness of FASD within the social circles and the families of pregnant women, and they in turn could contribute to supporting abstinence during pregnancy.

### Recommendation 8

The Committee recommends that the ACT Government provide more resourcing to the AOD sector that would support them to conduct more community education and awareness campaigns.

- 3.32. Research shows that alcohol is especially detrimental to adolescent brains. ATODA highlighted why awareness campaigns targeted at young women can be beneficial to preventing FASD:

It is important to note that yesterday's teenage drinker prone to intensive drinking episodes can become tomorrow's heavy drinker with an alcohol dependency. Early intervention with supportive, high-quality treatment is key to assisting young women experiencing dependence issues. It is critical this is provided prior to pregnancy for reasons including:

- The sooner someone with alcohol dependence seeks treatment the better the treatment outcomes are likely to be.

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<sup>63</sup> ATODA, *Submission 5*, p 1.

<sup>64</sup> ATODA, *Submission 5*, p 3.

<sup>65</sup> ATODA, *Submission 5*, p 2.

- The risk of harm from heavy drinking to the foetus at the earlier stages of pregnancy when women may be unaware of the pregnancy.<sup>66</sup>

3.33. At present, the AOD education in public secondary schools is insufficient, as explained by the Ted Noffs Foundation:

There is a strong need for alcohol and other drug (AOD) education within the ACT school system, especially for early high school students. Currently, all funding contracts for the AOD sector with ACT Health prevent us from providing expert drug education sessions to young people at this critical stage of their development. Education and information are key elements to working under a harm minimisation strategy. We receive, on average, 10 requests from local schools each term seeking support and information about AOD use for their students and communities. Our contracts only permit us to provide one-on-one counselling for individual young people. We do provide information sessions for teachers and parents, but this is at our own cost.<sup>67</sup>

### Recommendation 9

The Committee recommends that the ACT Government enables more flexibility in their contracts with the AOD sector to provide for AOD in ACT public schools, with particular focus on early secondary years.

## Other health programs

- 3.34. ACT health services, due to the territory's smaller population size, cannot service the number of subspecialties that, for example, the NSW hospital system can. As previously mentioned, families often seek services interstate, especially in Sydney. This results in their child's medical care being split across jurisdictions. According to the HCCA, navigating between and coordinating with health services across the border is a serious challenge.<sup>68</sup>
- 3.35. The Health Care Consumers Association has found that there is a persistent lack of communication between professional health services, resulting in missing information which is a 'massive problem for patient safety'.<sup>69</sup> Patients and their families are often relied on to relay information themselves, sometimes resorting to carrying print outs of patient records between doctors. This lack of direct communication between health services is a common problem for patients who live in the ACT but are required to access acute services in Sydney. For example, a patient may undergo surgery in Sydney and come home to recuperate in Canberra, where their local doctor might not have been sent the information required to oversee their post-operative needs. In extreme cases, parents are

<sup>66</sup> ATODA, *Submission 5*, p 2.

<sup>67</sup> Ted Noffs Foundation, *Submission 8*, p 3.

<sup>68</sup> Health Care Consumers' Association, *Submission 3*, p 2.

<sup>69</sup> Health Care Consumers' Association, *Submission 3*, p 3.

not understood or even believed by their local health care providers when they try to advocate for their children, as reported by the HCCA:

In one of these cases a child suffered a life-threatening event, but the emergency department did not have the appropriate information on file and were unaware of the specifics of the condition so refused to admit them. In this case it required the parents contacting the specialist in Sydney and them contacting the registrar at Canberra Hospital to tell them to admit the child. These sorts of delays are unacceptable in any life-threatening circumstances and they are completely avoidable.<sup>70</sup>

3.36. Communication breakdown is also seen to occur frequently when patients move from paediatric to adult services, or from in-patient to out-patient services.<sup>71</sup>

3.37. HCCA believe that some Sydney hospitals have liaison staff who assist patients in coordinating their care within the NSW system, however this service is only offered on an ad hoc basis in the ACT.<sup>72</sup> These types of staff, referred to as patient navigators, can facilitate communication between services and build medical literacy in families. As explained by the HCCA, their role is especially critical in times of emergency:

This kind of support is especially important in times of crisis or emergency when families may not have the emotional or mental capacity to navigate unnecessary barriers.<sup>73</sup>

3.38. The Committee understands that the Territory's population cannot support a health system which services all medical specialties and subspecialties. However, this means it is especially important for ACT residents to have easy access to out of state services. Quick and accurate communication between health services is essential for ensuring that patients receive accurate, evidence-based treatment.

### **Recommendation 10**

That Committee recommends that the ACT Government ensure continuity of health care for patients across jurisdictions and provide related support for their families.

3.39. As discussed above, not all medical specialties are adequately supported in the ACT. While travelling interstate to access specialist services is a possibility for families, it can be costly.<sup>74</sup> Furthermore, not all families have the time and money required. Accessing interstate health care is especially burdensome when it is on-going, such as in the case of accessing paediatric therapeutic equipment and services.<sup>75</sup>

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<sup>70</sup> Health Care Consumers' Association, *Submission 3*, p 3.

<sup>71</sup> Health Care Consumers' Association, *Submission 3*, pp 3 - 4.

<sup>72</sup> Alcohol Tobacco and Other Drug Association, *Submission 5*, p 5.

<sup>73</sup> ATODA, *Submission 5*, p 6.

<sup>74</sup> ACTCOSS, *Submission 9*, p 6.

<sup>75</sup> Health Care Consumers' Association, *Submission 3*, p 2.

- 3.40. Some families find that when they are prescribed therapies by Sydney doctors, they cannot access them through the NSW health system because they are not NSW residents. However, the therapies may not be available in the ACT at all, and funding to access the NSW services might not be available either, forcing the families to use the private system.<sup>76</sup> Sometimes these barriers to access can be bureaucratic rather than geographical, as reported by the HCCA:

There is the potential for the auxiliary health services to support children with neuromuscular conditions through the University of Canberra Hospital, however at present referrals must be done specifically through Canberra Hospital, even though they are both CHS services. For children who receive diagnosis as well as the majority of their treatment through specialists in Sydney, this can make accessing rehabilitative therapies in Canberra difficult.<sup>77</sup>

- 3.41. Another area which is under-serviced in the ACT is drug and alcohol outreach for young people. Ted Noffs reports that their counsellors are highly effective in reducing drinking rates, lowering incidents of crime, and promoting healthy family dynamics. However, they only have two counsellors on staff which limits them to 100 patients per year, and some parts of Canberra remain un-serviced in this area.<sup>78</sup>
- 3.42. As noted by several submitters including Advocacy for Inclusion, funding community care reduces reliance on expensive acute care services<sup>79</sup>. Community care services also have other benefits which will be discussed later in this report.

### Recommendation 11

The Committee recommends that the ACT Government increase funding to community organisations who provide specialised services for young people and their families.

- 3.43. Mental illness deserves a special focus in any discussion of health services in the ACT. Evidence shows that mental illness is the leading cause of chronic disease in the ACT, and that young people are over-represented in showing indicators of mental distress.<sup>80</sup> The Public Advocate and Children and Young People Commissioner notes in particular a 'persistent lack of mental health and therapeutic trauma support services for children and young people and the adverse consequences this has on their health'.<sup>81</sup>
- 3.44. Access to public mental health services is characterised by significant wait times, and this combined with the high costs of private services means that children and young people are not getting timely support, and in some cases give up on trying to get help at all.<sup>82</sup>

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<sup>76</sup> Health Care Consumers' Association, *Submission 3*, p 5.

<sup>77</sup> Health Care Consumers' Association, *Submission 3*, p 5.

<sup>78</sup> ACTCOSS, *Submission 9*, p 4.

<sup>79</sup> Advocacy for Inclusion, *Submission 7*, p 16.

<sup>80</sup> Public Advocate and Children and Young People Commissioner ACT, *Submission 4*, p 1.

<sup>81</sup> Public Advocate and Children and Young People Commissioner ACT, *Submission 4*, p 1.

<sup>82</sup> Public Advocate and Children and Young People Commissioner ACT, *Submission 4*, p 2.

Advocacy for Inclusion highlighted the ‘missing years’ of 8 to 12 as an area of particular concern:

This sits alongside the dearth of services for children in the middle years (8-12) who miss out on early intervention but are too young for youth services. Evidence is clear that low levels of wellbeing in this age group increases the risk of behavioural and mental health problems in later schooling. Mental illness is now the leading health concern for children of this age.<sup>83</sup>

- 3.45. The Ted Noffs Foundation advised that funding has largely been directed to mild and moderate mental illness, with patients with more complex needs often under-served.<sup>84</sup> Children who are victims of family violence require trauma specific therapies, and when this is not available they are at greater risk of becoming homeless or entering the child protection or youth justice systems.<sup>85</sup> Children with disabilities who have mental illness often present non-typical behaviours which may be viewed as ‘challenging’, resulting in families being excluded from accessing mental health care due to providers refusing service.<sup>86</sup> ATODA stated that there is a strong relationship between mental illness and risky behaviour in young people, however health services are often ‘siloes’ into specialties (mental health and AOD treatment) when the patient needs integrated care.<sup>87</sup> Finally, young people with mental disease are often unable to access NDIS support due to the requirement for them to be diagnosed with a permanent condition, which doctors are often reluctant to do.<sup>88</sup>
- 3.46. Advocates called for more funding for specialist mental health services, which includes cross-disciplinary, integrated care.<sup>89</sup> They recommended that funding for community mental health services be prioritised for prevention and early intervention.<sup>90</sup>

### Recommendation 12

The Committee recommends that the ACT Government provide increased access to affordable mental health support for children and young people in the ACT.

- 3.47. Despite making up 18% of the ACT population, people with a disability accounted for only 3.4% of staff in the ACT Health Directorate and 1.8% of staff in Canberra Health Services in the period 2019-2020.<sup>91</sup> Evidence before the Committee suggests that misconceptions and stigmas around disability are present in the ACT health system, and contribute to poor outcomes for patients, including, in extreme cases, a misinterpretation of medically caused

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<sup>83</sup> Public Advocate and Children and Young People Commissioner ACT, *Submission 4*, p 1.

<sup>84</sup> Ted Noffs Foundation, *Submission 8*, p 4.

<sup>85</sup> Public Advocate and Children and Young People Commissioner ACT, *Submission 4*, p 2.

<sup>86</sup> Advocacy for Inclusion, *Submission 7*, p 12.

<sup>87</sup> ATODA, *Submission 5*, p 1.

<sup>88</sup> Advocacy for Inclusion, *Submission 7*, p 12.

<sup>89</sup> Advocacy for Inclusion, *Submission 7*, p 16.

<sup>90</sup> Advocacy for Inclusion, *Submission 7*, p 17.

<sup>91</sup> Advocacy for Inclusion, *Submission 7*, p 14.

behaviour as criminal behaviour.<sup>92</sup> As said by Advocacy for Inclusion, increasing the numbers of people with a disability can contribute to an organisation's understanding of disability:

Employing people with disability can significantly enhance organisational culture, support workforce awareness and development, and positively impact service provision for others with disability.<sup>93</sup>

### **Recommendation 13**

The Committee recommends that the ACT Government employs more people with a disability across the ACT public service.

- 3.48. As stated by ACTCOSS in their submission, 'to achieve health choices and access for children/young people in particular, the role of the family cannot be overlooked.'<sup>94</sup> The family environment is critical in preventing disease and injury, spotting medical issues when they first appear, and in enabling early treatment.<sup>95</sup> Many of the solutions provided to problems covered by this report involve support at the parental/guardian level, for example aiding in transport costs, providing timely and accurate information on childrens' health care needs, and involving families as partners in medical care decisions.
- 3.49. The way that health outcomes could be improved for minors with support at the family and community level is well illustrated with the experiences of families of children with disabilities. Advocacy for Inclusion stated that carers of children with a disability are often placed in the complex position of both being over-relied on as information carriers and advocates in their children's medical experience, and simultaneously not valued as decision makers when it comes to their children's health.<sup>96</sup> Children with disabilities attend more medical appointments than the general population, however they are limited in their access to health care and they often rely on acute and emergency care due to the lack of preventative and early support services.<sup>97</sup> This is especially the case for children with mental illness or intellectual disability. They develop conditions which could have been prevented at a community level, however due to the lack of support in that area, they have high levels of presentation at emergency departments.<sup>98</sup>
- 3.50. Once they do come into the hospital environment, patients with disability can still come across barriers to care. Advocacy for Inclusion gave evidence that many ACT health service environments are not fully accessible.<sup>99</sup> They may lack ramps or have bright lights which

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<sup>92</sup> Advocacy for Inclusion, *Submission 7*, p 8.

<sup>93</sup> Advocacy for Inclusion, *Submission 7*, p 14.

<sup>94</sup> ACTCOSS, *Submission 9*, p 13.

<sup>95</sup> ACTCOSS, *Submission 9*, p 13.

<sup>96</sup> Advocacy for Inclusion, *Submission 7*, p 9.

<sup>97</sup> Advocacy for Inclusion, *Submission 7*, p 4.

<sup>98</sup> Advocacy for Inclusion, *Submission 7*, p 4.

<sup>99</sup> Advocacy for Inclusion, *Submission 7*, p 4.

are overly stimulating for patients with autism. This is an example which highlights what is called a ‘medically centred’ model of disability:

The medical model of disability places the ‘problem’ in the person, by viewing disability as an individual impairment to be treated, without acknowledging the environmental and social barriers that reduce independence and choice for people with a disability. Conversely, the social model of disability recognises the complex interplay between these barriers and individual-level biological and psychological factors. It also acknowledges that these barriers can reduce health outcomes and health equity for people with a disability.<sup>100</sup>

- 3.51. The Committee has been presented with many areas in ACT health services where improvements could be made to better the health care experience and outcomes for children and young people. An integrated health care system which acknowledges and values the importance of family support would go even further in achieving these aims.

#### **Recommendation 14**

The Committee recommends that the ACT review and improve the hospital and health care experience and processes for young people and their families, focusing on a family centred care model.

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<sup>100</sup> Advocacy for Inclusion, *Submission 7*, p 4

## 4. Conclusion

- 4.1. The Committee notes that this inquiry occurred during the COVID-19 pandemic and the ACT lockdown during the latter half of 2021.
- 4.2. Much like the other Committees of the Assembly, and government and legislative processes in general, the Territory-wide health emergency placed additional burdens on participants and the Committee recognises their commitment in assisting the Committee.
- 4.3. Irrespective of these circumstances, the Committee received high quality evidence, which has enabled the Committee to make some important recommendations, on FASD issues in particular.
- 4.4. The Committee again thanks everyone who contributed to this inquiry and this report, including all witnesses who appeared at a public hearing and those who made a written submission.

Mr Johnathan Davis MLA

Committee Chair

26 April 2022

# Appendix A: Witnesses

## Tuesday, 28 September 2021

- **Dr Devin Bowles**, CEO, Alcohol Tobacco and Other Drug Association ACT
- **Mr Lachlan Dean**, Programs Manager, Ted Noffs Foundation
- **Ms Caterina Giorgi**, CEO, Foundation for Alcohol Research and Education
- **Ms Stacy Rheese**, Team Leader, Policy, Advocacy for Inclusion
- **Dr Fiona Tito Wheatland**, Consumer Member, Health Care Consumers Association of the ACT

## Tuesday, 2 November 2021

- **Ms Rachel Stephen-Smith**, Minister for Health & Minister for Aboriginal and Torres Strait Islander Affairs & Minister for Families and Community Services
- **Associate Professor Boon Lim**, A/g Executive Director, Women, Youth and Children, Canberra Health Services
- **Ms Rebecca Cross**, Director-General, ACT Health Directorate
- **Mr Michael Culhane**, Executive Group Manager, Policy Partnerships and Programs, ACT Health Directorate

## Appendix B: Submissions

Number	Submission by	Received
1	ACT Government	10/06/21
2	Katherine O'Sullivan	09/06/21
3	Health Care Consumers' Association	09/06/21
4	ACT Public Advocate and Children and Young People Commissioner	17/06/21
5	Alcohol Tobacco and Other Drug Association ACT	02/07/21
6	Confidential	24/06/21
7	Advocacy for Inclusion	25/06/21
8	Ted Noffs Foundation	25/06/21
9	ACT Council of Social Service	25/06/21
10	Foundation for Alcohol Research and Education	25/06/21
11	Name Withheld	09/07/21

## Appendix C: Questions Taken on Notice

Number	Type of Question	Hearing date	Asked by	Asked to	Subject	Answer date
1	QToN	02/11/21	Davis	Ms Stephen-Smith	Fetal Alcohol Spectrum Disorder and Health Canberra Grants	19/11/21
2	QToN	02/11/21	Davis	Ms Stephen-Smith	Preventative Dental Care in Young Children	18/11/21
3	QToN	02/11/21	Milligan	Ms Stephen-Smith	Care coordination between ACT and interstate agencies	01/03/22
4	QToN	02/11/21	Pettersson	Ms Stephen-Smith	Update on the National Action Plan for the Health of Children and Young People 2020-2030	06/12/21
5	QToN	02/11/21	Davis	Ms Stephen-Smith	Access to Screening in Walk in Centres for Children	16/12/21
6	QToN	02/11/21	Pettersson	Ms Stephen-Smith	Screening and Health Assessment Data	02/11/21

# Appendix D: Health assessment and screening programs<sup>101</sup>

## Attachment A2: Health assessment and screening programs

The following breakdown the general health and screening programs provided across Canberra Health Services (CHS), Calvary Public Hospital Bruce and the Community Services Directorate (CSD), relative to the Terms of Reference.

### General health and screening programs

#### *Paediatric Outpatient Department*

The Paediatric Outpatient Department runs an extensive outpatient clinic service including:

- Cardiology Clinic
- Constipation Clinic
- Cystic Fibrosis
- Dermatology Clinic
- Diabetes Clinic
- ENT Clinic
- Endocrine Clinic
- Gastroenterology Clinic
- General Paediatrics Clinic
- Genetics Clinic
- Immunology Clinic
- Inflammatory Bowel Disease Clinic
- Neurology Clinic
- Neuromuscular Clinic
- Oncology/ Haematology Clinic
- Paediatric Fracture Clinic
- Paediatric Surgical Clinic
- Psychology Clinic
- Respiratory Clinic
- Rheumatology Clinic
- Sleep Clinic

#### *Hearing Test Programs*

National Newborn Hearing Screen - Delays in the identification and treatment of permanent childhood hearing impairment may profoundly affect quality of life in terms of language acquisition, social and emotional development, and education and employment prospects. All states and territories in Australia have universal newborn hearing screening including the ACT. Identified children are followed up by the CHS Audiology unit.

The Children's Hearing Service - The CHS, Women Youth and Children, Community Health Programs (WYCCHP) provide the Children's Hearing Service for children from 18 months to 18 years. This includes a full hearing assessment including history, otoscopy and tympanometry.

#### *Child Health Targeted Support Services*

Child Health Targeted Support Services offers a Community Paediatric service for children and adolescents under 16 years of age requiring assessment, treatment or review relating to suspected or established developmental delay or disability and behavioural or emotional disturbance, including the impact of abuse and/or neglect.

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<sup>101</sup> ACT Government, *Submission 1*.

#### *Children's Asthma Education Service*

This service provides up to date asthma information and education to health professionals and children and young people up to 18 years, with a diagnosis of asthma, and their families.

#### *Children and Young People Equipment Loans Scheme*

This service is managed by the CDS and loans equipment to assist with mobility, communication, and activities of daily living for children and young people in the ACT up to 16 years for a period of up to 3 months. Access to the service requires a referral from a suitable Allied Health professional.

#### *Genetic Service*

This service provides genetic counselling and clinical genetic consultations for people with concerns about medical findings in a pregnancy, or of an inherited condition in themselves, their children, or their family.

#### *Lesbian, Gay, Bisexual, Transgender, Intersex and Queer (LGBTIQ) paediatric and youth services*

Approximately 70 young people (up to the age of 18 years) are currently accessing care at the Centenary Hospital for Women and Children for a range of LGBTIQ related services.

#### *Nutrition services*

Offered through WYCCHP, this is a clinic-based nutrition assessment, counselling and advice service for infants, children, and young people aged under 25 years and all women during pregnancy and up to two years after birth.

#### *Outpatient Audiology*

This service provides assessment and onward referral of children with suspected, or risk of, hearing impairment.

#### *Paediatric and young adult diabetes service*

The paediatric and young adult diabetes service is a multidisciplinary service comprising of endocrinologists, diabetes nurse educators, a dietitian, and a social worker.

#### *Paediatric Outpatient Nurse Clinic*

This nurse clinic specialises in wound management, burns and supporting children with chronic health needs, gastrostomy, or nasogastric feeding tubes.

#### *Paediatric Palliative Care Service*

The Paediatric Palliative Care Service provides expert clinical care and leads the coordination of palliative care for children and young people with life-limiting conditions in the ACT.

#### *Physiotherapy-Juvenile Arthritis*

Individual physiotherapy is provided for paediatric clients attending rheumatology clinics.

#### *Physiotherapy-Paediatric Respiratory*

Physiotherapy is provided for chronic respiratory conditions such as Cystic Fibrosis.

#### *Psychology Chronic Illness Clinic*

This outpatient clinic provides clinical psychology services to children and adolescents who have a chronic illness.

#### *Speech Pathology-Paediatric videofluoroscopy service*

Videofluoroscopy assessments are provided for children under 18 years with dysphagia.

#### *Young Adult Transition Clinic*

A specialist diabetes/endocrine service at Canberra Hospital.

## Specific programs for different age ranges

The following breakdown of ACT public health services relevant to the Terms of Reference have been grouped by age range to highlight the evolving health care needs at different ages through a child or young person's life.

### Newborns to school aged children (0 to 12 years)

#### *Maternal and Child Health*

The Maternal and Child Health (MACH) service provides development checks at 0-4 weeks, 6-8 weeks, 4, 6, 12 and 18 months, 2, 3 and 4 years. Parents also complete a set of questions, the Parents Evaluation of Development Status (PEDS) that is provided at each health check from 6 months of age and helps the MACH nurse or GP identify concerns about the way the child is learning, developing, or behaving. Any identified concerns are referred to the appropriate service for further assessment and intervention, including Child Development Service, CHS Community Paediatric, and Children's Hearing Service. Support, education and information on all aspects of parenting is also provided.

#### *Newborn Hearing Screening Program*

Please see 'general health and screening programs'.

#### *Vision screening*

CHS offers an orthoptist service, which provides a secondary vision screening service for children from birth to six years if issues are raised following an initial MACH screen or Kindergarten Health Check.

#### *CHS Centenary Hospital for Women and Children Paediatric Blue Star clinic*

The Blue Star Clinic is an outpatient clinic that works with IMPACT (Integrated Multi Agencies for Parents and Children Together Program, see below) and the perinatal programs providing ongoing support for babies who are born with drug dependencies or other vulnerabilities as a result of parental substance use.

### *Integrated Multi-Agencies for Parents and Children Together Program (IMPACT)*

The IMPACT program is a multidisciplinary service which coordinates information sharing and service provision to make a positive difference to long term health outcomes for children. The program addresses gaps in the service system for families experiencing vulnerability and acts to strengthen the sector's capacity to support the complex needs of clients. The IMPACT Program is accessible to families who are pregnant and/or until the child is two years of age.

### *Multidisciplinary cleft palate clinic*

For children born with cleft lip or palate, this clinic offers surgical and post-operative management. Antenatal education is provided for expectant parents of children with cleft lip or palate.

### *Multidisciplinary feeding clinic*

This Speech Pathology and Dietetic tertiary referral service provides support for children with complex feeding issues.

### *Physiotherapy-Neonatal orthopaedics*

Physiotherapy led services are provided for congenital orthopaedic and neuromuscular disorders therapy.

### *Speech Pathology-Infant feeding clinic*

This Speech Pathology led outpatient service is for babies less than eight weeks of age with difficulties feeding due to an underlying medical issue.

### *Tresillian Queen Elizabeth II (QEII) Family Centre*

The ACT Government funds the following services for 0-3 year old's:

- Complex feeding and lactation issues
- Failure to thrive
- Unsettled babies
- Mood disorders
- Children at risk
- Special needs e.g. twins and multiple births
- Child or family behavioural problems
- Families with no parent support
- Sleep and settling strategies
- Diet and nutrition

In the 2019-2020 financial year, 958 parents and 980 children were admitted to QEII for a variety of services.

### *Child Development Service (CDS)*

The CDS provides allied health assessment, information, and referral services for children in the ACT at risk of developmental delay up to the age of 6 years who are not engaged with or likely to be eligible for support from the National Disability Insurance Scheme (NDIS) or their Early Childhood Early Intervention (ECEI) partner (EACH).

After assessment, CDS may offer brief, time-limited support to these children through group workshops or a 1:1 clinic (up to 5 sessions). There is a very small cohort where longer-term developmental monitoring is provided, such as the extremely premature infants who are at high risk of developing Cerebral Palsy. This is to ensure children can be linked with longer term supports as soon as the potential impact of prematurity becomes evident.

CDS does not provide longer term therapeutic intervention for children. If it is identified that a child would benefit or requires access to ongoing therapeutic supports, there are two referral pathways:

- NDIS ECEI partner (EACH) for assessment of eligibility if the child is likely to receive a funded support package through the NDIS; and
- If identified as unlikely to be eligible for NDIS, families are referred to private allied health services as currently there are no government funded long term therapeutic early intervention services for this cohort.

If a child is referred to CDS and they are currently involved or likely to be eligible for an NDIS support package (for example: a child with a diagnosed disability such as Fetal Alcohol Syndrome – a list D diagnosis) this child is not eligible for CDS services. However, they would be supported to contact the NDIS ECEI partner (EACH) as the gateway to an NDIS support package.

Specific services offered through CDS include:

#### Intake and Drop-In-Clinics (DIC)

This service provides a pathway for parents and other referrers to seek advice, find out if further services are necessary and where these services are available. DIC are delivered at Tuggeranong Child and Family Centre, Gungahlin Child and Family Centre and West Belconnen Child and Family Centre in addition to the Child Development Service at the Holder site.

Approximately 70% of children accessing the CDS are under 5 years of age at the time they received services, and approximately 6% of families accessing the CDS identified as Aboriginal and Torres Strait Islander.

The service has a range of Allied Health Professionals who offer developmental assessments and advice/referral to families who have concerns regarding their child's development. The service also has Early Childhood teachers who provide supported playgroups. The playgroups focus on assisting parents to promote development through play. This is offered to families experiencing vulnerability and complex support needs.

## Allied Health Services

Speech Pathology - Speech pathologists at the CDS offer a range of services including assessment, advice and strategies to assist parents to support the development of their children aged up to 6 years, in the areas of:

- Understanding language;
- Combining words into sentences to express meaning;
- Speaking clearly so others can understand the message;
- Stuttering on words and sounds;
- Social communication skills such as difficulties interacting with others;
- Breast and bottle feeding;
- Transition to solids;
- Parent workshops/groups or short term 1:1 clinic for families up to 5 sessions; and
- Ongoing therapeutic intervention is not provided by the CDS speech pathologists.

Physiotherapy - Physiotherapists at the CDS offer a range of services including assessment, advice, and strategies to assist parents to support the development of their children aged up to 6 years, in the areas of:

- Foot position such as in-toeing, out-toeing, flat feet;
- Clumsiness;
- Delays in reaching milestones such as sitting, standing, walking;
- Delays in gross motor development such as jumping, hopping, climbing;
- Difficulties with catching, throwing, kicking balls;
- Parent workshops/groups or short term 1:1 clinic for families up to 5 sessions; and
- Ongoing therapeutic intervention is not provided by the CDS physiotherapists.

Occupational Therapy – Occupational Therapists at the CDS offer a range of services including assessment, advice and strategies to assist parents to support the development of their children aged up to 6 years, in the areas of:

- Fine motor skills such as grasping toys and pencils, managing small items including buttons and zips and coordinating the movements of their fingers to complete activities;
- Self-care activities including brushing teeth, getting dressed, using utensils and toileting;
- Play skills including interacting with toys, playing alongside and with other children and connecting with parents/carers through play;
- Appropriate sensory responses to allow your child to participate in everyday activities such as completing routine hygiene activities (washing hair, brushing

teeth, getting dressed), eating a varied diet and being able to settle for play and learning opportunities;

- Parent workshops/groups or short term 1:1 clinic for families up to 5 sessions; and
- Ongoing therapeutic intervention is not provided by the CDS occupational therapists.

Social work - Social Workers at the CDS work with families to identify needs and refer and link in with appropriate supports. Families eligible for social work support are those that are already engaged with the service.

### Autism Assessments

Free autism assessments are provided for children aged up to 12 years. A referral from a Paediatrician or Psychiatrist is required.

### Therapy Services

Ongoing therapeutic intervention is not provided by the CDS for children and young people diagnosed with Autism. If further supports are required after assessment, families are referred to EACH. EACH is the NDIS service partner responsible for assessing eligibility for NDIS services and/or to private therapy and health services.

### *Child and Family Centres*

The Child and Family Centres in West Belconnen, Tuggeranong and Gungahlin offer a range of initial screenings, assessments, referrals and group programs for children. Services are available for children pre-birth to 8 years; however, selected services can be offered to children up to 12 years of age.

The group programs are focused on general health and wellbeing, including mental health, and families requiring further assistance are referred to specialist services. CDS also provide Drop-in Clinics at the centres. Many of these group programs are run in partnership with the community sector and government directorates.

**Table 1: Programs offered at Child and Family Centres**

Group Facilitated by	Program	Target Group & Service Delivery
Child and Family Centre	Drop-in parenting support	<p>Parents and carers are invited to visit their local Child and Family Centre to chat with a trained professional about parenting, ask questions and to get information. This can lead to ongoing, one-to-one support with Child and Family Workers.</p> <p>Staff are available to speak with parents and service providers — Monday to Friday from 9.00 am to 5.00 pm.</p>

<b>Group Facilitated by</b>	<b>Program</b>	<b>Target Group &amp; Service Delivery</b>
Child and Family Centre	Ongoing Support	Child and Family Workers are available to provide ongoing support to children and their families. No two families are the same, so Child and Family Workers can provide a tailored service to families.
Child and Family Centre	Children's Behaviour and Emotional Wellbeing Clinic	Consultation clinics for parents and carers of children under 8 years to provide information on child development and behaviour, relationships and strategies to support these concerns.
Child and Family Centres and Canberra Regional Community Services	Circle of Security relationship-based parenting program	This international and widely-researched program provides opportunities to develop and enhance a secure relationship between parents and their children. Parents will learn how to recognise, understand and meet their children's emotional needs in order to prevent and manage behavioural and emotional difficulties. This is an eight week, small group program which uses observation, reflection, practice and discussion. The group is appropriate for parents of children aged birth to 8 years.
Child and Family Centre	Bringing Up Great Kids	A program to help parents explain and reflect on their parenting style and their children's behaviour. The program provides parents with a greater understanding of how to meet their children's needs and communicate with them.
Child and Family Centre	Cool Kids	A group for primary school children aged 8–12 years, focusing on teaching them better ways to manage anxiety.
Child and Family Centre	Cool Little Kids	A group for parents of children aged 3–8 years, helping them learn strategies to assist their anxious child.
Child and Family Centre	Tuning into Kids	A parenting program that aims to give parents and carers helpful ways of teaching their child to develop skills for good emotional intelligence. Tuning into Kids teaches parents awareness and regulation of their own and their child's emotions. It also teaches parents skills to assist children to verbally label and manage their emotions, and to problem solve. The program assists parents in guiding their children's behaviour within appropriate limits.
Child and Family Centre	GET UP (Group Engaging The	A group for young parents under 25 years where parents can meet new friends, tap into creative skills, play with their child/children, connect with support and find out useful parenting tips.

Group Facilitated by	Program	Target Group & Service Delivery
	Under 25 Parents)	
West Belconnen Child and Family Centre and Canberra Regional Community Services.	Deadly Bubs	A supported playgroup for Aboriginal and Torres Strait Islander preschoolers and their families, focusing on strengthening community and cultural connections and promoting positive child–parent relationships.
Child and Family Centres and partners	Koori Playgroup	A supported playgroup for Aboriginal and Torres Strait Islander children birth to 5 years and their parents and carers.
West Belconnen Child and Family Centre and partners	Koori Boys	An opportunity for young Aboriginal and Torres Strait Islander boys to come together and explore opportunities to connect with culture in a culturally safe and supported environment. This group focuses on healthy mind, body and spirit, building strong connections to culture and Country, growing young people as future leaders and strengthening relationships between schools, communities and families.
West Belconnen Child and Family Centre and partners	Koori Girls ‘Yurwang Gulwan’	An opportunity for young Aboriginal and Torres Strait Islander girls to come together and explore their connection with culture in a culturally safe and supported environment. This group focuses on healthy mind, body and spirit, building strong connections with culture and Country, growing young people as future leaders and strengthening relationships between schools, communities and families.
West Belconnen Child and Family Centre and partners	Learn, Giggle and Grow	Parents and children have the opportunity to interact and play in a safe and supported environment. The emphasis is on encouraging parents to engage with their children in play, enrich the parent–child relationship and help parents build confidence. Groups run from weeks 2–9 of each school term.
West Belconnen Child and Family	Mullabu Yura Boys Group	A group for primary school aged Aboriginal and Torres Strait Islander boys. The group, which is supported by male mentors, meets weekly to

Group Facilitated by	Program	Target Group & Service Delivery
Centre and partners		celebrate culture and connection with each other and their community.
Child and Family Centre	Parents as Teachers	A monthly home visit program to help parents recognise everyday learning opportunities in their children's lives. During visits, trained parent educators provide parents with practical information and guidance to help their child develop skills essential for later learning. Emphasis is placed on developing children's thinking and curiosity, language, motor and social skills. Support can start later in the prenatal period and may continue until a child reaches 3 years of age.
Child and Family Centre and partners	POPPY (Parents' Opportunity to Participate in Play with their Young)	A supported group for mums and dads focusing on mental health, wellbeing and resilience. Parents can meet other parents and share experiences while having fun playing with their children.
Gungahlin Child and Family Centre and partners	Tiddas Girls Group	A group for primary school aged Aboriginal and Torres Strait Islander girls. The group meets weekly to celebrate culture and connection to each other and their community. A range of fun and creative activities are offered to help build confidence and self-esteem.
West Belconnen Child and Family Centre and partners	Yurwang Bullarn Strong Women's Group	A group focusing on community connectedness. It provides local Aboriginal and Torres Strait Islander women with an opportunity to socialise regularly and engage in activities addressing art and culture, self-care, health and wellbeing
Gungahlin Child and Family Centre	Atfaal Family Playgroup	A group for Muslim families with children under 5 years living in Gungahlin. The group aims to build links with the community and provide access to parenting information and services.
Child and Family Centre	Multicultural Group	A playgroup to assist multicultural families with children from birth to 5 years to settle into the community by providing them with a range of support services. The playgroup also supports families by nurturing their child's development through play.

Group Facilitated by	Program	Target Group & Service Delivery
West Belconnen Child and Family Centre	South Sudanese Group	A group for South Sudanese families with children from birth to 5 years. The group aims to build links with the community and improve access to parenting information and services.

## Kindergarten aged children (4 to 6 years)

### *Kindergarten Health Check*

The Kindergarten Health Check (KHC) is a universal screening program offered to all children in the ACT in their first year of formal schooling. The KHC has been offered in the ACT for over 30 years and consists of two components:

1. A CHS physical health check: height, weight and BMI, and a vision and hearing screen; and
2. Academic Unit of General Practice (AUGP) parent questionnaire and parent surveys; the Parents Evaluation of Development Status (PEDS), Strengths and Difficulties and Adverse Childhood Experiences surveys.

The KHC is culturally embedded in the ACT and over 85% of eligible children completed the KHC in 2019.

Results of the physical KHC are sent to the parent (with referral options) and to the GP, if one is nominated by the School Health Team and results of the questionnaires are sent to the nominated GP by the AUGP. If no GP is nominated but there is a high level of concern the parent is contacted regarding seeking further help.

**Table 2: 2019 Kindergarten Health Check data**

Participation status for 2019 Kindergarten Health Check	2019 student numbers
Number of children who could participate in KHC	6019
Number who completed Parental questionnaire component of KHC	5560
Number who completed school nurse physical check component of KHC	5178

In early 2020, the school nurse physical check component of the KHC was cancelled due to COVID-19, with limited space offered later in 2020 at special KHC clinics for parents to self-refer if they were worried.

Together these instruments provide important screening information about which children are at higher risk of future mental and physical health challenges. Results of the physical

KHC are sent to the parent, along with referral options, and to the GP, if one is nominated by the SHT. Results of the questionnaires are sent to the nominated GP by the AUGP. If no GP is nominated, but there is a high level of concern, the parent is contacted by a nurse regarding pathways to seek further help.

The ACTHD has partnered with the ANU and Capital Health Network (CHN) to provide GPs with tools and training to assist them to consider the KHC results and take appropriate courses of action in partnership with their patient families. CHN has linked KHC into its web-based assessment, management and referral pathway support system that assists primary care clinicians to navigate evidence-based clinical management and referral options available locally across the ACT and south east NSW.