



**LEGISLATIVE ASSEMBLY**  
**FOR THE AUSTRALIAN CAPITAL TERRITORY**

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STANDING COMMITTEE ON HEALTH AND COMMUNITY WELLBEING  
Mr Johnathan Davis MLA (Chair), Mr James Milligan MLA (Deputy Chair),  
Mr Michael Pettersson MLA

## Submission Cover Sheet

Review of ACT health programs for  
children and young people

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# **Review of ACT health programs for children and young people**

***Submission***

## About Advocacy for Inclusion

Advocacy for Inclusion incorporating People with Disabilities ACT is a leading independent organisation providing dedicated individual and self-advocacy services and training, information and resources in the ACT. We deliver reputable national systemic advocacy informed by our extensive experience in individual advocacy and community and government consultation.

As a Disabled People's Organisation, the majority of our organisation, including our Board of Management, staff and members, are people with disabilities. Advocacy for Inclusion speaks with the authority of lived experience and is strongly committed to advancing opportunities for the insights, experiences and opinions of people with disabilities to be heard and acknowledged.

Advocacy for Inclusion operates under a human rights framework. We uphold the principles of the United Nations *Convention on the Rights of Persons with Disabilities* and strive to promote and advance the human rights and inclusion of people with disabilities in the community. Advocacy for Inclusion is a declared public authority under the *Human Rights Act 2004*.

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Advocacy for Inclusion acknowledges the Aboriginal and Torres Strait Islander peoples as Traditional Custodians of the lands where we live, learn and work.



We respect and celebrate diversity of individuals, including those amongst the lesbian, gay, bisexual, trans, and intersex communities and we value and promote inclusion and diversity in our communities.

## Background

Advocacy for Inclusion (AFI) incorporating People with Disability ACT (PWDACT) welcome the opportunity to make a submission to the Legislative Assembly Standing Committee on Health and Community Wellbeing on the adequacy, availability and implementation of ACT Health programs for children and young people.

AFI incorporating PWDACT is hopeful that this review will result in improvements to the wellbeing of children and young people with disability, in addition to the social and economic wellbeing of the ACT. This is as current barriers to health care impact the human rights of children and young people with disability, whilst negatively contributing to ACT's public health statistics and costs. As will be shown, the current system also contributes to an increased burden on the criminal justice system.

Children and young people with disability are a distinct, yet diverse category of health-care consumers. They tend to have poorer health outcomes and higher rates of co-occurring conditions.<sup>1</sup> The latest ABS report on 'Disability, Ageing and Carers' in Australia stated that the rates of disability in children are 3.7% of 0-4 year-olds; 9.6% of 5-14 year-olds; and, 9.3% of 15-24 year-olds.<sup>2</sup> Among children under 15 years-old, intellectual disability is the most common type.<sup>3</sup>

The ACT has 2,616 participants, aged 0-24 years old, who are NDIS participants.<sup>4</sup> Public data on the number of children and young people with disability, who are not NDIS participants, is less readily available. In 2016, 2981 children enrolled in ACT schools and 6683 people, aged 18-24 years old, enrolled in the Vocational Education and Training system self-identified as having a disability.<sup>5</sup> Due to issues with identification and diagnosis, these statistics most likely underrepresent disability in the ACT. Aboriginal and Torres Strait Islander children experience a higher prevalence of disability than other Australian children.<sup>6</sup>

## Barriers to health care in the ACT

Children and young people with disability can face an array of issues in accessing both general and specialised health and assessment programs. It is essential that the Standing Committee ensures

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<sup>1</sup> World Health Organisation, 'World Report on Disability' (Report, 2011), 263.

<sup>2</sup> Australian Bureau of Statistics, 'Disability, Ageing and Carers, Australia: Summary of Findings' (Report, 24 October 2019) <<https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>>.

<sup>3</sup> VicHealth, 'Disability and health inequalities in Australia' (Research Summary, August 2012), 2.

<sup>4</sup> National Disability Insurance Agency, 'Explore data' (17 June 2021) National Disability Insurance Agency <<https://data.ndis.gov.au/explore-data>>.

<sup>5</sup> ACT Government, 'A Picture of ACT's Children and Young People' (Report, December 2016), 10.

<sup>6</sup> Biddle, N, Yap, M and Gray, M. 'CAEPR Indigenous Population Project: 2011 Census Papers' (Census Paper, No. 6/2013, 2011), 2.

all these areas are addressed to ensure that ACT Health programs adequately meet the needs of children and young people with disability.

## **Prevalence of medical 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 disability.<sup>7</sup> 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 disability.<sup>8</sup> In our experience, the medical model of disability remains dominant in the ACT medical profession and contributes to the numerous concerns outlined below.

## **Reliance on acute services**

While children with disability typically attend more 'health-related' appointments than children without disability, their "actual access to health care services may be more limited."<sup>9</sup> This is reflected in their underuse of preventative services and reliance on high-cost services such as emergency departments (EDs),<sup>10</sup> which arises due to a lack of adequate early support services and the failure of existing services to meet their needs.

In AFI's experience, people with disability may make frequent presentations to EDs due to their needs not being met by community supports. This has been most prevalent in our clients with intellectual disability and mental illness. The research reflects our experiences, indicating that admission rates are higher for people with disability with "conditions that could have been prevented through appropriately individualised preventative health care or early disease management."<sup>11</sup>

## **Reliance on the NDIS**

AFI is concerned about an increasing reliance in the ACT solely upon the National Disability Insurance Scheme (NDIS) to provide support for people with disability, following the loss or

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<sup>7</sup> Australian Federation of Disability Organisations, 'Social Model of Disability' (2021) *AFDO*

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<sup>8</sup> Kavanagh, A. 'Disability and public health research in Australia' (2020) 44(3) *Australian and New Zealand Journal of Public Health*, 262.

<sup>9</sup> Australian Institute of Health and Welfare, 'Children with disabilities in Australia' (Cat no DIS38, 2004), xiv.

<sup>10</sup> Drainoni, M et al. 'Cross-Disability Experiences of Barriers to Health-Care Access: Consumer Perspectives' (2006) 17(2) *Journal of Disability Policy Studies*, 102.

<sup>11</sup> Eliza Hull, 'Preventable hospitalisation rates 4.5 times higher for people with intellectual disabilities, research reveals' (15 June 2021) *ABC News* <<https://www.abc.net.au/news/2021-06-14/people-with-intellectual-disabilities-hospitalisation-research/100209410>>.

reduction of wider community supports in the rollout of the NDIS. This is problematic because approximately only one in ten people with disability will have access to the NDIS. Where these services are not publicly available, non-NDIS participants may be excluded from accessing important preventative services due to financial barriers. Excluding lower-socio economic groups from preventative care will ultimately contribute to higher presentations in acute medical settings. AFI also highlights upcoming potential legislative reform to the NDIS, which may result in reduced support or further restrictions on access to the scheme and an additional reliance on community support.

### Case study: Sexual Health and Family Planning ACT (SHFPACT)

SHFPACT have various services available for young people with disability. However many are costly or dependent on NDIS funding; namely, the 'Me & You (disability)' 2021 program is \$2025.00 for non-NDIS participants or \$2022.72 for NDIS participants.<sup>12</sup> This particular program is an important preventative health service for young people with disability who experience the same range of sexual needs and desires as people without disability, yet face many difficulties meeting their sexual needs and accessing sexual health care. However, the high cost for non-NDIS participants excludes many young people from accessing the service.

## Accessibility

Accessibility refers to both physical accessibility, such as ramps and bathrooms, and sensory accessibility, such as lighting and noise levels. Inaccessible environments can completely prevent children and young people with disability from being able to access a service or it may create distress and escalated behaviour upon attendance.

Currently, many ACT Health programs operate in ways which are not accessible. For example, places such as ACT EDs are ill-suited as they can overstimulate young people with sensory sensitivity, causing challenging behaviours. Mental health patients, children with intellectual disability and those with Autism Spectrum Disorder (ASD) would benefit from the creation of 'quiet places' and sensory environments in hospitals.<sup>13</sup>

## Financial barriers

Children and young people with disability are more likely to come from a lower socio-economic background. Consequently, they are less likely to be able to afford out-of-pocket costs or have access to private health insurance. This is problematic because insured children are more likely

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<sup>12</sup> SHFPACT, 'Me & You (disability)' (2021) *Training and Workshops* <<https://shfpact.org.au/development-training/328-men-you-disability>>.

<sup>13</sup> Productivity Commission, 'Inquiry Report Mental Health Volume 2' (Inquiry Report, No. 95, 30 June 2020), 603.

than uninsured children to have regular health care.<sup>14</sup> Additionally, in 2018, the ACT Primary Health Network Area's average out-of-pocket cost per patient was \$85 above the national average and second only to Sydney.<sup>15</sup>

Furthermore, many Canberran's must travel interstate for specialist treatment, such as psychiatrists, psychologists, eating disorder in-patient treatment,<sup>16</sup> or integrated paediatric treatment.<sup>17</sup> This is as there is a shortage of private and public health services in the ACT. The associated costs render travel unaffordable for many families, meaning children and young people miss out on assessments and treatment. Even where families have the financial means, the time and sacrifices required to access interstate health services makes it impossible for many ACT families.

## **Professional competency specific to disability**

Access to health care for children and young people can be significantly affected by a lack of disability awareness and disability-specific skills in health professionals. Inadequate skills lead to poor communication between the professional and the patient, a lack of flexibility and understanding on behalf of the practitioner, increased difficulty implementing management plans, examination difficulties and an increased likelihood of misdiagnosis and diagnostic overshadowing.

AFI has supported numerous clients to engage with health professionals, including through communicating their needs and clarifying management plans. In AFI's experience, many ACT Health staff have demonstrated inadequate awareness of accessible or adaptive communication, inclusive practices and supported decision making (SDM). In some cases, concepts such as SDM appear to be given only tokenistic mention or are seen as a 'box ticking' exercise, with little to no evidence of implementation in practice. We believe that this is largely due to a lack of understanding and skills to implement these practices, based on a lack of specific training and education.

Health professionals also often withhold adjustments for disability. AFI clients have reported that health staff have repeatedly failed or refused to make adjustments when communicating information or responding to needs. Adaption to the needs of the child or young person with disability, including communication and flexibility (for example, in appointment lengths), is a major

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<sup>14</sup> Newacheck, P. et al. 'Access to Health Care for Children with Special Health Care Needs' (2000) 105(4) *Official Journal of the American Academy of Paediatrics*, 760.

<sup>15</sup> Australian Institute of Health and Welfare, 'Patients' out-of-pocket spending on Medicare services 2016-17' (Australian Government Report, Cat. No HPF 35, 16 August 2018), 6.

<sup>16</sup> Thalia Roy, 'Where is Canberra's promised \$13.5 million eating disorder treatment centre?' (19 June 2020) *ABC News* <<https://www.abc.net.au/news/2020-06-19/where-is-the-eating-disorder-treatment-clinic-canberra/12371524>>.

<sup>17</sup> Campbell, D. et al. 'Parents' and Service Providers' Experiences of Accessing Health Services from an Intellectual Disability Health Team' (2021) 12 *Journal of Primary Care & Community Health* <<https://journals.sagepub.com/doi/pdf/10.1177/21501327211014068>>.

factor in ensuring children and young people receive quality health care. AFI's clients have also experienced inconsistency in the quality of services and a feeling that they have no other options. Receiving inconsistent health care as a child may lead to poorer health outcomes as an adult. Ultimately, this leads to higher long-term costs for the government and thus there is a strong financial incentive to support young children with disability to access adequate health care.

## Misdiagnosis/Diagnostic overshadowing

Diagnostic overshadowing is when a medical professional assumes that a patient's complaint is related to their disability. This is a significant risk when treating professionals do not have specific disability knowledge and training. It is particularly common where children and young people have intellectual disability. For example, recent research has found that "ADHD is a common problem in children with neurological disabilities and may be underdiagnosed due to overshadowing of somatic, physical or syndromal features of the disability."<sup>18</sup>

Siloing of services contributes to misdiagnosis and diagnostic overshadowing in the ACT. This occurs where a service caters to a certain need at the expense of others and it can result in gaps in treatment, unclear treatment pathways and increased difficulties navigating and accessing care. For example, the Community Paediatric and Child Health Service (CP&CHS) will not see children who have "an acute medical problem that is not related to development or behaviour."<sup>19</sup> Additionally, Child and Adolescent Mental Health Services (CAMHS) appears unable to provide assessments for ADD/ADHD or ASD,<sup>20</sup> and AFI has been told young people with ASD have been unable to access adequate mental health support through CAMHS due to their lack of specialist knowledge of ASD.

Currently, many children entering kindergarten in the ACT receive a Health Check. These checks are a significant opportunity for early identification of disability and health needs, if conducted by appropriately skilled professionals with disability awareness. However, some disability schools such as Cranleigh and Malkara are exempt from these health checks.<sup>21</sup> While these schools have adopted the 'HealthCare Access At School model', AFI has concerns that children may miss out on wholistic screening.

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<sup>18</sup> Hendriksen, J. et al. 'Diagnostic overshadowing in a population of children with neurological disabilities: A cross sectional descriptive study on acquired ADHD' (2015) 19(5) *European Journal of Paediatric Neurology*, <10.1016/j.ejpn.2015.04.004>.

<sup>19</sup> ACT Government, 'Community Paediatric and Child Health' (28 May 2019) *ACT Government Health* <<https://www.health.act.gov.au/services-and-programs/women-youth-and-children/children-and-youth/community-paediatric-and-child>>.

<sup>20</sup> Ibid.

<sup>21</sup> ACT Government, 'Canberra Hospital and Health Services Clinical Procedure: Kindergarten Health Check' (Procedure, CHHS17/015, 14 February 2017).



## Stigma and misconceptions

Stigma and misconceptions associated with children and young people with disability contribute to their participation in, and the effectiveness of, health screening programs. This may include practitioners preconceived ideas of disability and the child or young person's capabilities, which can lead to insensitivity and negative experiences for the person with disability. Negative interactions at a young age may lead to a life-long "distrust of health providers, failure to seek needed care, and reliance upon self-treatment."<sup>22</sup>

Children and young people with disability may present with challenging behaviour. This term refers to behaviour that challenges other people "but may be functional for the person with a disability."<sup>23</sup> Challenging behaviour can be exacerbated or caused by inaccessible physical environments (e.g. excessive stimuli) or staff who are inadequately equipped to manage such behaviours. This may have a multitude of negative effects. For example, the person may be prevented from returning to the service or their carer may choose not to come back to the practice because they are afraid of 'causing a scene'. In some cases, it will mean that the child or young person does not receive a physical examination. AFI has seen examples where parents have been unable to access disability services due to waitlists or service gaps. Simultaneously, mainstream health services which lack disability awareness have dismissed parents' concerns about their child's behaviour, construing the child as 'acting out' or lacking parental discipline. At a later stage, these behaviours have been identified by disability specialists as resulting from unidentified health conditions.

Stigma and misconceptions are also pertinent when considering the overrepresentation of young people with disability, including FASD, involved with child protection and youth justice. In some cases, behaviours associated with disability and undiagnosed health conditions are interpreted as offending behaviour. This contributes to an over-representation of people with disability in the criminal justice system. This system is a blunt and inadequate mechanism to support people with cognitive disabilities, such as FASD, who may have "poor impulse control, developmental delay, poor memory, difficulties with abstract concepts and difficulties with planning and following through on goals."<sup>24</sup> AFI has worked with clients where such behaviours have resulted in their apprehension and caused significant trauma. In extreme cases, it results in the arbitrary detention of people with disability. This causes additional health and behavioural concerns, ultimately incurring more costs to the ACT across both health and justice systems.

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<sup>22</sup> World Health Organisation, above n. 1, 77.

<sup>23</sup> National Collaborating Centre for Mental Health, 'Challenging Behaviour and Learning Disabilities: Prevention and Interventions for People with Learning Disabilities Whose Behaviour Challenges' (NICE Guideline, No. 11, May 2015).

<sup>24</sup> Commonwealth of Australia, 'Effective approaches to prevention, diagnosis and support for Fetal Alcohol Spectrum Disorder' (Senate Standing committee Report, ISBN 978-1-76093-197-1, March 2021), 15.

## Carer relationships

There are two main concerns related to carers and guardians of children and young people with disability. On the one hand, AFI has had client's express concerns that medical professionals do not listen to their carers or parents. On the other hand, there is a structural over-reliance on carers and guardians to identify health problems and to seek out appropriate services.<sup>25</sup> This is not always possible and is not a reliable method of health screening. Relevantly, children with disability are more likely to have a primary carer with a disability.<sup>26</sup> Consequently, relying on carers may be problematic where the carer experiences similar barriers to accessing health care; for example, in communication.

## Informed choice

Children and young people are often denied a voice when accessing health care services. This is more apparent for children and young people with disability. It is essential that professionals consider both the caregiver and the young person's needs and opinions in their delivery of health care. This is essential to ensure that the child's right to expression in all matters affecting them is upheld.<sup>27</sup>

## Fetal Alcohol Spectrum Disorder (FASD)

FASD is one of the leading causes of preventable birth defects and intellectual disability. Many of the issues discussed in the previous section remain relevant for children and young people with FASD. However, children and young people with FASD are also often positioned at the intersection of other vulnerable identities. Namely, FASD is more prevalent in the Aboriginal and Torres Strait Islander population and amongst children and young people in contact with the child protection system and youth justice system.

Despite the complexities and need for adequate treatment, obtaining a diagnosis and accessing treatment is notoriously difficult due to structural barriers, financial barriers, and cultural barriers, such as stigma and culturally inappropriate programs.<sup>28</sup> Structurally, the assessment and treatment options for FASD are significantly limited. Canberra does not have a diagnostic clinic, and thus children and young people are expected to travel to places such as Sydney to obtain an

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<sup>25</sup> Lennox, N. and Kerr, M. 'Primary health care and people with an intellectual disability: the evidence base' (1997) 41(5) *Journal of Intellectual Disability Research*, 4.

<sup>26</sup> Australian Bureau of Statistics, above n. 2.

<sup>27</sup> *Convention on the Rights of the Child*, United Nations, open for signature 20 November 1989, UNTS 1577, (entered into force 2 September 1990), Article 12(1).

<sup>28</sup> Foundation for Alcohol Research and Education, 'Election commitment sought for Canberra FASD clinic' (9 September 2017) *FARE* <<https://fare.org.au/election-commitment-sought-for-canberra-fasd-clinic/>>.

assessment.<sup>29</sup> Given the intersectional disadvantages that many children with FASD experience, this is untenable and results in many children not receiving care.

Many existing programs are focused on preventing the immediate cause of the FASD: alcohol consumption during pregnancy. In the ACT, these programs include harm reduction and education strategies, such as Pregnant Pause. However, it is also important to look beyond the immediate cause of the disorder and examine the causes of the causes. These causes refer to the economic, social, and cultural milieu that people live in and are known as the social determinants of health.<sup>30</sup> The benefits of using this framework to prevent and treat FASD include its recognition that:

While dominant discourse suggests that FASD is preventable by abstention from alcohol during pregnancy, a broader perspective would indicate that alcohol and pregnancy is a far more complex issue, that is, bound in location, economics, social and cultural views of health.<sup>31</sup>

This recognition facilitates the consideration of factors such as mental health issues, violence, education,<sup>32</sup> housing, poverty, stigma and shame.<sup>33</sup> Comprehensive programs for children and young people with FASD will necessarily provide wholistic support to the young person and their family across their economic, social and cultural worlds.

AFI highlights the lack of progress in the ACT since MLA Elizabeth Kikkert brought a *Bimberi Youth Detention Centre, Screening Practices, Foetal Alcohol Spectrum Disorder* motion, amended and agreed to in 2018, including identifying 'best practice approaches and tools for the diagnosis and treatment of FASD, both in juvenile detention settings and in the community'.<sup>34</sup>

While AFI acknowledges that the *Healthy Centre Review of Bimberi Youth Justice Centre 2020* states that there are 'some positive developments happening at Bimberi in relation to disability'<sup>35</sup>, we note that identified 'key areas for improvement' continue to include fundamental areas such as 'data gathering on the prevalence of disability among young detainees, screening for disability, communicating with young detainees in disability-responsive ways and staff training on disability awareness'.<sup>36</sup> AFI emphasises the need for increased action in enhancing screening practices in

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<sup>29</sup> Foundation for Alcohol Research and Education, above n. 28.

<sup>30</sup> Hamilton, S. Doyle, M. and Bower, C. 'Review of Fetal Alcohol Spectrum Disorder (FASD) among Aboriginal and Torres Strait Islander people' (25 May 2021) 2(1) *Analysis and Policy Observatory: Australian Indigenous Health Bulletin*, 9.

<sup>31</sup> Baldry, D. and Felsk, A. 'An examination of the social determinants of health as factors related to health, healing and prevention of foetal alcohol spectrum disorder in a northern context--the Brightening Our Home Fires Project, Northwest Territories, Canada' (2013) 5(72) *International Journal of Circumpolar Health*, <<https://pubmed.ncbi.nlm.nih.gov/23984290/>>.

<sup>32</sup> Hamilton, S. Doyle, M. and Bower, C. above n. 31.

<sup>33</sup> *Ibid.*

<sup>34</sup> Legislative Assembly for The Australian Capital Territory, 'Minutes of Proceedings' (Parliamentary Minutes, No 57, 9 May 2018) <[https://www.parliament.act.gov.au/\\_\\_data/assets/pdf\\_file/0006/1198311/MoP057F1.pdf](https://www.parliament.act.gov.au/__data/assets/pdf_file/0006/1198311/MoP057F1.pdf)>.

<sup>35</sup> ACT Inspector of Correctional Services, 'Report of a healthy centre review of Bimberi Youth Justice Centre 2020' (Report of a Review of a Detention Place, 2021), 12.

<sup>36</sup> *Ibid.*

line with the *Australian Guide to the Diagnosis of Fetal Alcohol Spectrum Disorder*, improving data collection and screening and additional training to youth justice staff.

## **Mental health programs for children and young people with disability in the ACT**

Children and young people with disability often have coexisting mental illness, however they are less likely to receive treatment and support for the mental health condition.<sup>37</sup> We have observed three main areas of concern for children and young people with disability trying to access mental health support in the ACT. These are in addition to universal concerns, such as an inadequate number of health professionals in the public system.

### **Accessibility of mainstream services**

As discussed above, accessibility includes the physical and sensory accessibility. However, it must also encompass the promotion and delivery of services. Mental health services are often communication-heavy, which can complicate participation for children and young people with communication difficulties.<sup>38</sup>

Services for children and young people in the ACT include Headspace and CAMHS. These often have long wait-times, and many young people are unaware of different options. Additionally, AFI understands that young people with disability, such as ASD, have been unable to access adequate support from CAMHS.<sup>39</sup> This is concerning given the high rate of co-occurrence.

### **Recognition and identification of mental health issues**

Children and young people with disability are more likely to have atypical presentations of mental illness.<sup>40</sup> This is particularly pertinent for people who have ASD, FASD or intellectual disability. As a result, common mental health screening and assessment tools may fail to adequately identify mental illness in this population and professionals require focused training on selecting appropriate assessment tools.<sup>41</sup>

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<sup>37</sup> Hastings, R. et al. 'What About the Mental Health of Kids with Intellectual Disability?' (25 November 2014) *The Australian & New Zealand Mental Health Association* <<https://anzmh.asn.au/child-mental-health/mental-health-kids-intellectual-disability/>>.

<sup>38</sup> Weise, J. and Troller, J. 'Preparedness and training needs of an Australian public mental health workforce in intellectual disability mental health' (2018) 43(4) *Journal Of Intellectual & Developmental Disability*, 436 & 437.

<sup>39</sup> Health Direct, 'Child and Adolescent Mental Health Services (CAMHS) – Northside' (accessed 21 June 2021) *Health Direct* <<https://www.healthdirect.gov.au/australian-health-services/20133970/child-and-adolescent-mental-health-services-camhs---northside/services/belconnen-2617-56-lathlain-street>>.

<sup>40</sup> Weise, J. and Troller, J. above n. 37, 436.

<sup>41</sup> Whittle, E. et al. 'Barriers and Enablers to Accessing Mental Health Services for People with Intellectual Disability: A Scoping Review' (2018) 11(1) *Journal of Mental Health Research in Intellectual Disabilities*, 93.

Zeilinger, E. et al. 'CAPs-IDD: Characteristics of Assessment Instruments for Psychiatric Disorders in Persons with Intellectual Developmental Disorders' (2013) 57(8) *Journal of Intellectual Disability Research* 737.

Professionals often have difficulty distinguishing between mental illness and challenging behaviour.<sup>42</sup> This contributes to misdiagnosis and may result in the child or young person receiving no treatment or incorrect treatment. Consequently, young people with disability and mental illness are less likely to get appropriate support from mental health services and are more likely to become engaged with other institutions, such as the criminal justice system.

## Responses from services and supports

There is currently a lack of services providing adequate behaviour support for people with disability and mental illness in the ACT. Furthermore, many services (including NDIS Service Providers) can refuse service to someone presenting with challenging behaviours. The result is that people who require complex support are often excluded from mental health services.

Additionally, there is a lack of disability specific treatment services and a siloed approach to care; for example, in the ACT it would be unclear where a young person with an eating disorder and an intellectual disability would seek help. The ACT has a Mental Health Service for People with Intellectual Disability. However, it is not available to those under the age of 17.

Finally, children and young people with mental illness are often unable to access NDIS Supports. However, as discussed, there is an increasing reliance by the Government for such supports to be provided by the NDIA. The statistics show that only 27 people aged 7-18 years old receive NDIS support for psychosocial disability in the ACT.<sup>43</sup> This is largely because the NDIS requires them to prove permanence. However, "health professionals have been reluctant to confirm that someone has a likely to be permanent impairment as a result of their mental health condition before the age of 25."<sup>44</sup> Furthermore, "when interpreting evidence against the likely permanence of impairment requirement, the NDIA considers how long the person has had the impairment, and to what extent treatment options have been explored (noting that the impairment may alleviate with age-appropriate development)."<sup>45</sup>

Consequently, many children and young people with mental illness, in addition to another disability, have difficulties obtaining territory and federal supports.

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<sup>42</sup> Weise, J. and Troller, J. above n. 37, 438.

<sup>43</sup> National Disability Insurance Agency, above n. 4.

<sup>44</sup> National Disability Insurance Agency, 'Frequently Asked Questions (FAQs) for mental health professionals supporting people applying for the NDIS' (10 March 2021) *Mental health and the NDIS*, 7-8, <<https://www.ndis.gov.au/understanding/how-ndis-works/mental-health-and-ndis#factsheets-and-resources>>.

<sup>45</sup> National Disability Insurance Agency, 'Accessing the NDIS, A Guide for Mental Health Professionals' (August 2017) *Mental health and the NDIS* <<https://www.ndis.gov.au/understanding/how-ndis-works/mental-health-and-ndis#factsheets-and-resources>>.

## Health programs for young women and girls with disability in the ACT

Young women and girls with disability are “at greater risk of abuse in their family.”<sup>46</sup> However, violence against children with a disability is under researched and poorly understood.<sup>47</sup> This gap in knowledge obscures the prevalence of domestic violence in families who care for a child with a disability, and consequently limits the workforce’s capacity to detect and respond appropriately. Additionally, “the responses of children and young people with a disability to the trauma associated with DV may be confused with the effects of a particular impairment.”<sup>48</sup> As a result, detecting and responding to domestic and family violence when working with a child or young person with a disability is complexified by diagnostic overshadowing.

Harm from domestic and family violence can be exacerbated by failures to identify and respond appropriately. AFI believes that health programs can play a significant role in either protecting children and young people from domestic and family violence, or perpetuating harm, such as through creating care plans which include perpetrators. Consequently, health programs need to proactively identify and respond to domestic and family violence to minimise harm.

## Recommendations

### **1. Prioritise the resourcing, design and implementation of a Disability Health Strategy.**

The systemic barriers to health care access and the health equity of people with disability need to be addressed through targeted support of a dedicated Disability Health Strategy. To support its success, such a strategy must be adequately resourced through the design and development phases and effective codesign with people with disability must be undertaken.

AFI notes that existing research overwhelmingly focuses on the wellbeing and experiences of carers of children with disability; neglecting the well-being and health care experiences of the children and young people themselves.<sup>49</sup> AFI emphasises the importance of codesign with people with disability, including children, in designing effective measures to address current gaps. We note that the Convention on the Rights of Persons with Disabilities, Article 4 (3) states “[i]n the development and implementation of legislation and policies to implement the present Convention,

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<sup>46</sup> Baldry, E. Bratel, J. and Breckenridge, J. ‘Domestic Violence and Children with Disabilities: Working Towards Enhancing Social Work Practice’ (2006) 59(2) *Australian Social Work*, 186.

<sup>47</sup> Ibid.

<sup>48</sup> Ibid, 189.

<sup>49</sup> Lewellyn, G. and Leonard, H. ‘Indicators of Health and Well-being for Children and Young People with Disabilities: Mapping the Terrain and Proposing a Human Rights Approach’ (Literature Review, Australian Research Alliance for Children and Youth (ARACY), 2010).

and in other decision-making processes concerning issues relating to persons with disability, States Parties shall closely consult with and actively involve persons with disability, including children with disability, through their representative organizations.”<sup>50</sup>

AFI recommends that existing resources developed by the ACT community sector, including the ACT Council of Social Service (ACTCOSS)’s comprehensive *Imagining Better* report<sup>51</sup> are also used as guidance in the development of a Disability Health Strategy.

- 2. ACT Health services, including Canberra Health Services, are fully resourced and supported to progress and implement Disability Action and Inclusion Plans.**
- 3. Provide comprehensive disability awareness and education training for health service staff, with a focus on improving communication and access, and increasing health literacy and supported decision making for people with disability.**

Workforce training and development is essential to ensure staff are skilled to support and implement disability reform, particularly progressive changes such as increased supported decision making. During consultations for the new National Disability Strategy “[p]articipants consistently noted that health professionals needed a better understanding of disability in order to make services more effective, accessible and inclusive.”<sup>52</sup> Training should also include awareness on how social determinants and other factors influence the health and safety of people with disability; including, domestic and family violence and appropriate approaches to risk identification and response.

- 4. Increase the number of people with disability employed by ACT Health services.**

Employing people with disability can significantly enhance organisational culture, support workforce awareness and development, and positively impact service provision for others with disability. During the 2019-2020 period, the ACT Health Directorate only recorded 3.4% of employees as identifying as having a disability<sup>53</sup> (exceeding the Directorate’s target),<sup>54</sup> while Canberra Health Services recorded only 1.8% of their workforce identifying as people with disability.<sup>55</sup> In comparison, the Australian Public Service goal is “to increase the employment of

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<sup>50</sup> United Nations, Convention on the Rights of Persons with Disabilities, Article 4 (3).

<sup>51</sup> See ACT Council of Social Service, ‘Imagining Better Reflections on access, choice and control in ACT health services for people with disability’ August 2019.

<sup>52</sup> The Social Deck, ‘A New National Disability Strategy Stage 2 consultations: Report on Targeted Workshops’ (Department of Social Service, Disability and Carers Consultation Report, April 2021), 18.

<sup>53</sup> ACT Health Directorate, ‘Annual Report 2019-20’ (Report, Publication Number 200993, 2020), 183.

<sup>54</sup> Ibid, 178.

<sup>55</sup> Canberra Health Services, ‘Annual Report 2019-20’ (Report, Publication Number 20/0586, 2020), 57.

people with disability across the APS to 7% by 2025.”<sup>56</sup> Considering this, alongside the fact that almost 18% of Australians have a disability,<sup>57</sup> AFI recommends that employment targets regarding people with disability in ACT Health services are significantly increased to support effective community representation and diversity of staff, and to enhance culture and awareness within these services. This recommendation should also be considered in relation to the ACT’s implementation of the National Disability Strategy.

#### **5. Increase early support for disability, including identification and response.**

There is a significant need to improve early support for children and young people with disability, including FASD. AFI recommends that existing services are made more accessible and inclusive through upskilling staff to better identify and respond to disability needs. We also recommend the provision of additional services to meet demand, including through the creation of new services and the expansion of existing services. Early disability support may include identification and response measures, alongside family, respite and behaviour support.

Children and young people disengaging from education or at risk of becoming involved with the youth justice system require particular focus. Early support is essential to prevent the escalation of unidentified and unaddressed disability needs and the funnelling of children and young people with disability into acute health services and the criminal justice system.

The ACT spends a significant amount on detention-based supervision of young people.<sup>58</sup> Nationally, evidence indicates that children and young people within youth justice have a high prevalence of mental health disorders and cognitive disability.<sup>59</sup> Additionally, children and young people within youth justice with complex and multiple disabilities have a significantly lower average age of first contact with police.<sup>60</sup> They also have higher rates of contact. This means that the youngest children in youth justice are highly likely to have disabilities and unmet support needs.

While improvement in disability screening and support is needed within Bimberi Youth Justice Centre,<sup>61</sup> adequate identification and support must be provided prior to engagement with the youth justice system. No child in the ACT should only receive screening and support for disability after being sentenced or detained on remand.

AFI calls on the ACT Health Directorate, in partnership with the Community Services Directorate, to prioritise increased early disability support in line with the Early Support by Design reform under

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<sup>56</sup> Australian Public Service Commission, ‘Australian Public Service Disability Employment Strategy 2020-25’ (Strategy, ISBN 978-0-6489351-4-8, 3 December 2020) <<https://www.apsc.gov.au/publication/australian-public-service-disability-employment-strategy-2020-25>>.

<sup>57</sup> Australian Bureau of Statistics, above n. 2.

<sup>58</sup> Productivity Commission, ‘Report on Government Services 2021: Youth justice services’ (Report, 20 January 2021), Figure 17.10 and Table 17A.20.

<sup>59</sup> Baldry, E. ‘Vulnerable young people with complex support needs and the criminal justice system’ (2016) *South Australia Disability Justice Plan Symposium*.

<sup>60</sup> Ibid.

<sup>61</sup> ACT Inspector of Correctional Services, above n. 35.



the Disability Justice Strategy. This recommendation should also be considered in relation to the ACT's implementation of the National Disability Strategy and the recommendations of the final report of *Our Booris, Our Way*.

Additionally, AFI supports the development of a First 1000 Days Strategy in partnership with the community.<sup>62</sup>

## **6. Establish specialist services in the ACT to meet demand.**

There is substantial need for a range of specialist services (including psychiatrists and psychologists) in the ACT, with many children and young people forced to access interstate services where possible.

AFI supports the establishment and sufficient resourcing of "a multidisciplinary service to support young people who have mental health needs co-occurring with trauma, disability and drug and alcohol abuse,"<sup>63</sup> and recognises the need for further specialist support initiatives.

AFI notes the ongoing need for specialist allied health professionals to meet demand for Autism Spectrum Disorder (ASD) assessments,<sup>64</sup> initiatives to address the mental health needs of people with Intellectual Disability and ASD, and effective behaviour support (including carer information and support) for children and young people presenting with challenging behaviour.

AFI also notes that the Foundation for Alcohol Research and Education (FARE) has repeatedly called for the establishment of a Fetal Alcohol Spectrum Disorder clinic in the ACT.<sup>65</sup> This need remains unmet.

AFI supports the establishment and improvement of "programs that target and support youth mental health, eating disorders, alcohol/drug use/mental health, First Nations mental health, First Nations suicide prevention & postvention and respite for mental health carers."<sup>66</sup>

## **7. Fund community services to provide mental health and disability services to prevent acute presentations, and to support transition out of acute facilities into community options.**

AFI notes that in 2019-2020, the ACT was \$118,108 (15%) over the original target total cost for acute services.<sup>67</sup> Funding community supports to reduce preventable hospital admissions will help

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<sup>62</sup> ACT Government, 'Parliamentary and Governing Agreement 10<sup>th</sup> Legislative Assembly for the Australian Capital Territory' (Parliamentary and Governing Agreement, 2 November 2020), Appendix 3, 19.5.

<sup>63</sup> ACT Government, 'Budget 2020-2021, Statements C.' (Budget, 2020-2021), 4.

<sup>64</sup> Community Services Directorate, 'Annual Report 2019-20' (Report, ISSN 2206-9968, 2020), 94.

<sup>65</sup> Foundation for Alcohol Research and Education, above n. 29.

See also Foundation for Alcohol Research and Education, 'ACT Drug Strategy Action Plan 2018-2021' August 2018, 21-22.

<sup>66</sup> ACT Government, above n. 59, Appendix 5, 16.6.

<sup>67</sup> ACT Government, 'Canberra Health Services, 2019-2020 Annual Report' (Government Report, 2020), 224.

reduce these costs, whilst also enabling people with disability to access appropriate health care. AFI recommends priority is given to mental health early intervention and prevention, addressing the socioeconomic determinants of mental health and meeting gaps in disability support.

AFI notes with concern that *Recommendation 172*, that the ACT Government continue to work closely and collaborate with the NDIA, is marked as 'No longer required' within the ACT Health Directorate Annual Report 19-20.<sup>68</sup> As discussed, there is an ongoing need to identify and close gaps between health and disability supports, including for those who are ineligible for the NDIS or who experience gaps in NDIS support. This is particularly important if NDIS access and participation is further restricted by legislative reform.

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<sup>68</sup> ACT Health Directorate, above n. 51.