

Disability

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Overview

There are many different kinds of disability and they can result from accidents, illness or genetic disorders. A disability may affect mobility, ability to learn things, or ability to communicate easily and some people may have more than one disability. A disability may be visible or hidden, may be permanent or temporary and may have minimal or substantial impact on a person's abilities. Although some people are born with disability, many people acquire a disability.

Disability can be grouped into eight categories (Australian Network on Disability, 2016), which include;

- Physical - affects a person's mobility or dexterity
- Intellectual - affects a person's abilities to learn
- Mental illness - affects a person's thinking processes
- Sensory - affects a person's ability to hear or see
- Neurological - affects a person's brain and central nervous system
- Learning disability
- Physical disfigurement
- Immunological - the presence of organisms causing disease in the body

In 2015, the disability prevalence rate in Australia was 18.3% (approximately 4.3 million Australians), where disability was defined as any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months (Australian Bureau of Statistics, 2016). The rate of disability was similar to the rate seen in Australia in 2012 and 2009 (18.5%) (Australian Bureau of Statistics, 2011, Australian Bureau of Statistics, 2013).

In the ACT, the rate of disability also remained comparable from 2012 to 2015 (15.8% and 16.2%, respectively), equating to approximately 62,000 ACT residents having a disability in 2015, while around, 4.9% of ACT residents (18,800 people) had a profound or severe core activity limitation (Australian Bureau of Statistics, 2016).

The proportion of the population living with disability increases considerably by age, which can explain the lower disability rate in the ACT compared to Australia, with the ACT having a lower proportion of people aged over 65 years (Australian Bureau of Statistics, 2013).

In 2015, 78.5% of Australian's with disability reported a physical condition as their main long-term health condition (causing them the most problems when completing everyday activities) and 21.5% reported mental or behavioural disorders (in 2012 the proportions were 81% and 19%, respectively) (Australian Bureau of Statistics, 2016, Australian Bureau of Statistics, 2013). Consistent with 2012

findings, the most commonly reported physical conditions in 2015 were back problems (13.5%) and arthritis (12.7%) (Australian Bureau of Statistics, 2016). For mental and behavioural disorders, the most commonly reported conditions were intellectual and developmental disorders (6.3%) and depression and mood affective disorders (4.2%).

The type of long-term health condition causing people the most problems varied with age (Australian Bureau of Statistics, 2013). Children were most likely to have asthma or an intellectual and development disorder. Working age people were most likely to report back problems, a disease of the nervous system or a mood affective disorder such as depression. While older people were most likely to report arthritis and related disorders or a disease of the circulatory system such as heart disease, stroke or high blood pressure (Australian Bureau of Statistics, 2013).

Disability can affect anyone at any time and most people can expect to live part of their life with disability. At birth, Australians can expect to live, on average, over one-fifth of their lives with some level of disability, e.g. boys born in 2015 have a life expectancy of around 80 years and could expect to live an average of 63 years free of disability and around 17 years with some level of disability, including 5 years with severe or profound core activity limitation (Australian Institute of Health and Welfare, 2017).

Health status of Australians with disability

While some people can live healthily with disability, people with disability are likely to experience poorer health outcomes. People with disability experience significantly poorer self-assessed health than those without disability (Australian Institute of Health and Welfare, 2016).

In 2011-12, people aged under 65 years with severe or profound core activity limitation were 3.3 times as likely as those without disability to have three or more long-term health conditions (74% versus 23%) (Australian Institute of Health and Welfare, 2016). Half (50%) of people aged under 65 years with severe or profound core activity limitation had mental health conditions, compared with 8% for those without disability. They were also more likely to acquire a mental health condition before the age of 25 years (39% versus 28%).

In 2011-12, adults aged 18-64 years with severe or profound activity limitation had a higher prevalence of overweight or obesity compared with people without disability (70% and 60% respectively), and were 1.7 times more likely as those without disability to be obese (43% versus 25%) (Australian Institute of Health and Welfare, 2016).

People with disability are more likely to smoke, with those aged 15-64 years with severe or profound disability twice as likely as those without disability to smoke daily (31% versus 15%) and 1.8 times as

likely to start smoking before the age of 18 years (41% versus 23%) (Australian Institute of Health and Welfare, 2016).

Adults aged 18-64 years with severe or profound core activity limitation were 20 times as likely as those without disability to have a very high level of psychological distress (22% versus 1%) (Australian Institute of Health and Welfare, 2016). The relationship between mental and physical conditions and severity of disability are complex. For example, people with disability and depression may have a greater tendency to develop diabetes, but then the resulting changes in lifestyle due to diabetes may maintain or increase severity of the depression and disability (Australian Institute of Health and Welfare, 2016).

Early detection and intervention of long-term health conditions for people with disability may increase the potential to reduce the prevalence and severity of disability and needs for services later in life.

Other population characteristics of people with disability

People with disability may face additional difficulties accessing and participating in things such as education and employment. Participation in education can be affected by the support, assistance and equipment available for people with disability. Nationally in 2015, 14.9% of those aged 15 years and over with disability reported having completed a Bachelor degree or above compared to 28.7% of those without disability (Australian Bureau of Statistics, 2016). In the ACT there was a higher rate of those aged 15 years and over with disability having completed a Bachelor degree at 30.9%, but also a higher rate of those without disability completing a Bachelor degree (43.9%). Of older Australians (aged 65 years and over) in the ACT with disability, 15.5% reported Year 8 or lower as their highest level of education completed, compared with 7.7% of those without disability (Australian Bureau of Statistics, 2016).

In 2015, 53.4% of working age people with disability were in the labour force, compared to 83.2% of people with no disability, in the ACT the rate was 60.1% and 85.5% respectively (Australian Bureau of Statistics, 2016). Those with a profound or severe limitation were less likely to be in the labour force (25.0%) than those with a mild limitation (58.9%) (Australian Bureau of Statistics, 2016). People with disability were also less likely than those without disability to be working full time (27.0% and 53.8%, respectively).

People with disability were more likely to have lower levels of income than those without disability. In 2015, approximately half (49.4%) of people with disability lived in households in the lowest two

quintiles for equivalised gross household income, compared with 24.3% of those without disability (Australian Bureau of Statistics, 2016).

People with disability often need assistance and support to be independent and participate in social and economic situations that others do not need assistance with. In 2015, more than half of Australians with disability needed assistance with at least one activity of daily life (Australian Bureau of Statistics, 2016). Assistance was most commonly needed with health care (29.3%), property maintenance (26.9%) and household chores (23.5%). Those with profound limitation reported the greatest need for assistance with mobility (88.3%) and health care (77.3%), such as administering injections or taking medication.

Aids and equipment can assist people with disability by improving their functioning, promoting their independence and increasing their participation in social and economic life. In 2015, half (50.2%) of those people with disability used aids or equipment because of their condition, consistent with 2012 findings (Australian Bureau of Statistics, 2016). People living alone were more likely to use aids or equipment, while the majority of those living in cared accommodation used aids or equipment.

Access to transport is a critical element of participation in society and can be difficult where disability is present. In 2015, 14.7% of people with disability couldn't use any form of public transport, 6.1% could use some but not all forms, and 78.5% reported they could use all forms of public transport (Australian Bureau of Statistics, 2016). Of those reporting difficulty, the main types of difficulty experienced were: access issues due to steps; difficulty getting to the stops or stations; fear and anxiety and; lack of seating or difficulty standing.

Disability Services in the ACT

For the past 10 years, the Disability Information Service has provided a centralised point of contact for people with disability, their families and carers, and other members of the ACT community seeking information about disability matters within the ACT. However, as a result of the transition to the National Disability Insurance Scheme (NDIS) this services ceased operation in September 2016.

The shift from a block funding model (e.g. from the ACT Government) to individualised funding under the NDIS has affected many small organisations in the ACT. For example, Autism Asperger ACT was forced to consider closing down the organisation under the new funding structure, in a move that would have been disastrous for families who depend on its service (Gorrey, 2016). Fortunately the organisation has been able to negotiate a merger with Marymead, another local service that provides support for children, young people and their families.

National Disability Insurance Scheme (NDIS)

The National Disability Insurance Scheme (NDIS) launched in July 2013, after years of discussion about the need for a major reform of disability services in Australia. In 2010, The Australian Government asked the Productivity Commission to carry out a public inquiry into a long-term disability care and support scheme. The Productivity Commission received over 1,000 submissions from people with disability and the disability sector and their report was released in August 2011 (Marsh, 2017).

Subsequently, in 2011, the Council of Australian Governments (COAG) agreed to the need for a reform to disability services through a National Disability Insurance Scheme (NDIS). An agreement was reached at a July 2012 COAG meeting to proceed with the launch of the NDIS, and three jurisdictions; South Australia, Tasmania and the Australian Capital Territory, agreed to participate in the launch. ACT was the first whole jurisdiction to trial the NDIS. In March 2013, the NDIS legislation was passed and the *NDIS Act 2013* was created, along with the scheme. The agency responsible for delivering the scheme is known as the National Disability Insurance Agency (NDIA). The Medicare levy increased from 1.5% to 2% on 1 July 2014, to fund the NDIS (National Disability Insurance Agency, 2016e).

The NDIS is a new way of funding individualised support for people with disability (including psychosocial disability) that involves more choice and control and a lifetime approach to a person's support needs. The NDIS is the largest social reform since Medicare and is being implemented at a rapid rate when compared with the introduction of other national reforms.

The ACT began the two year transition to the NDIS on 1 July 2014, for people aged up to 65 years with an impairment that is likely to be permanent and the impairment makes it difficult to take part in everyday activities. Initial estimates were that 4,278 people with disabilities in the ACT would be covered by the Scheme, however, at 31 December 2016 there were 5,998 deemed eligible and 5,541 participants with an approved plan (National Disability Insurance Agency, 2017b).

People were brought into the Scheme in a gradual way (according to date of birth or academic year at school age) to ensure staff, operations and services were ready to be delivered effectively and sustainably (National Disability Insurance Agency, 2016c). The National Disability Insurance Agency (NDIA) contacted existing clients of disability services, about transitioning into the Scheme. Existing national and state-based services and supports continued until eligible people started their plan with the NDIS.

In the ACT, people over the age of 65 who are currently accessing an ACT Government funded disability service will be provided with continuity so their support remains consistent with current arrangements (ACT Community Services, 2016).

To be eligible for the NDIS, people living in the ACT need to meet age and residence requirements (e.g. Australian citizen, hold a permanent visa or a Special Category Visa) as well as disability or early intervention requirements.

Disability requirements to be eligible for the NDIS include (National Disability Insurance Scheme, 2016):

- the disability is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition **and**
- your impairment is, or likely to be, permanent **and**
- your impairment substantially reduces your ability to take part effectively in activities (i.e. communication, social interaction, learning, mobility, self-care or self-management), or perform tasks or actions unless:
 - you have assistance from other people on most days, **or**
 - you have assistive technology, equipment (other than common items such as glasses) **or**
 - you can't take part effectively even with assistance or aides and equipment; **and**
- your impairment affects your capacity for social and economic participation **and**
- you are likely to require support under the NDIS (and not another service system such as the health system) for your lifetime.

An impairment that varies in intensity, for example because the impairment is of a chronic episodic nature, may still be permanent, and the person may require support under the NDIS for the person's lifetime, despite the variation.

Early intervention requirements include (National Disability Insurance Scheme, 2016):

- you have one or more identified intellectual, cognitive, neurological, sensory or physical impairments that are, or are likely to be, permanent **or**
- you have one or more identified impairments that are attributable to a psychiatric condition **or**
- you are a child aged under 6 years with a developmental delay which results in:
 - substantially reduced functional capacity in one or more of the areas of self-care, receptive and expressive language, cognitive development or motor development **and**

- results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of extended duration, and are individually planned and coordinated; and
- there is evidence that getting supports now (early intervention) will help you by:
 - reducing how much help you will need to do things because of your disability in the future; **or**
 - mitigating, alleviating, or preventing deterioration of your functional capacity or improving such functional capacity **or**
 - helping your family and carers to keep helping you **and**
- those supports are most appropriately funded through the NDIS, and not through another service system (such as the health system).

At 30 June 2016, of the 29,847 active participants with approved plans in Australia, 58% were found eligible for the Scheme because they met the disability requirements, and 41% of participants met the early intervention requirements (National Disability Insurance Agency, 2016f). One percent of participants met the early intervention requirements and now meet the disability requirements. Younger participants were more likely to meet the early intervention requirements which aim to improve, stabilise or lessen the impact of the person's impairment on their functional capacity. Almost all participants aged over 18 years met the disability requirements.

Table 1 describes the characteristic of the ACT cohort of NDIS participants with approved plans as of 31 December 2016, and compares to the Australian cohort. There were 5,998 participants deemed eligible in the ACT and 5,541 had approved plans (National Disability Insurance Agency, 2017c). During the December 2016 quarter 485 new participants were deemed eligible in the ACT. As seen below, 36% of NDIS participants in the ACT had an intellectual disability as their primary disability, similar to the percentage in Australia (38%). However, the ACT had a lower percentage of NDIS participants with autism than Australia (20% and 28% respectively) and a higher percentage of NDIS participants with approved plans with a psychosocial disability (12% and 6% respectively).

Table 1: Information about participants with NDIS approved plans as of 31 December 2016, ACT and Australia

	ACT (31 Dec 2016)	Australia (31 Dec 2016)
Total (number)	5,541	61,215
Aboriginal and Torres Strait Islander	4.3%	5.2%
Age (years)		
0-6	21%	16%
7-14	23%	29%
15-18	8%	9%
19-24	6%	9%
25-34	7%	8%
35-44	9%	8%
45-54	11%	10%
55-64	12%	10%
65+	3%	1%
Primary Disability		
Intellectual Disability	36%	38%
Autism	20%	28%
Psychosocial Disability	12%	6%
Cerebral Palsy	4%	5%
Other Physical	7%	5%
Other Neurological	4%	4%
Other Sensory/Speech	5%	3%
Acquired Brain Injury (ABI)	2%	2%
Hearing Impairment	4%	2%
Visual Impairment	2%	2%
Multiple Sclerosis	3%	2%
Stroke	1%	1%
Spinal Cord Injury	1%	1%
Other	0%	0%

Source: (National Disability Insurance Agency, 2017b)

As of 30 June 2016, the ACT had developed 5,572 plans, including initial and subsequent plans. Approximately 700 plans in the ACT (17%) contained only a single type of support. Both in the ACT and nationally, 99% of plans included supports for daily living (National Disability Insurance Agency, 2016f). Other common supports in the ACT include, independence (66% of plans); community, social and civic participation (30%); health and wellbeing (20%); home living (15%); relationships (13%); employment (10%); and education (3%).

Only 20% of ACT plans were approved within 90 days of an access request being submitted during the third quarter of 2015-16 (National Disability Insurance Agency, 2016f). This was the fourth

lowest proportion of all trial sites behind Tasmania (6%), Victoria (10%) and South Australia (11%), while the Northern Territory (89%) and NSW-Nepean Blue Mountains (88%) had the highest rates of plans approved within 90 days of an access request being submitted. The ACT's rate of 20% in the third quarter of 2015-16, decreased from 26% in the previous quarter. However, the ACT had the highest number of plan reviews in the third quarter of 2015-16, which may have diverted resources.

At 30 June 2016, the ACT continued to have the highest rate of self-managed plans nationally (financial management), at 15%, with other states ranging between 1-13% and the national average at 7% (National Disability Insurance Agency, 2016f). The ACT had the second-highest rate of combination managed plans (48%) and the lowest rate of agency managed plans (37%) in the trial sites.

As shown in Table 2, from 30 June 2016 to 31 December 2016 an additional 849 participants were deemed eligible for the NDIS in the ACT, while the number of 'in progress' requests decreased dramatically (from 596 to 145) (National Disability Insurance Agency, 2016f, National Disability Insurance Agency, 2017c). However, during this time the number of access requested deemed ineligible increased considerably, from 437 to 752, sitting at 31 December 2016 at a rate of 10.6% of all access requests made. This is the highest ineligibility rate of all the states and territories and much higher than the Australian rate (5.5%) (National Disability Insurance Agency, 2017c). Feedback from consultation suggests some of the access requests that were deemed ineligible were due to GPs not adequately describing the 'impacts on daily life' of their patient's disabilities.

Table 2: Proportion of access requests made in the ACT and nationally, at 30 June 2016 and 31 December 2016.

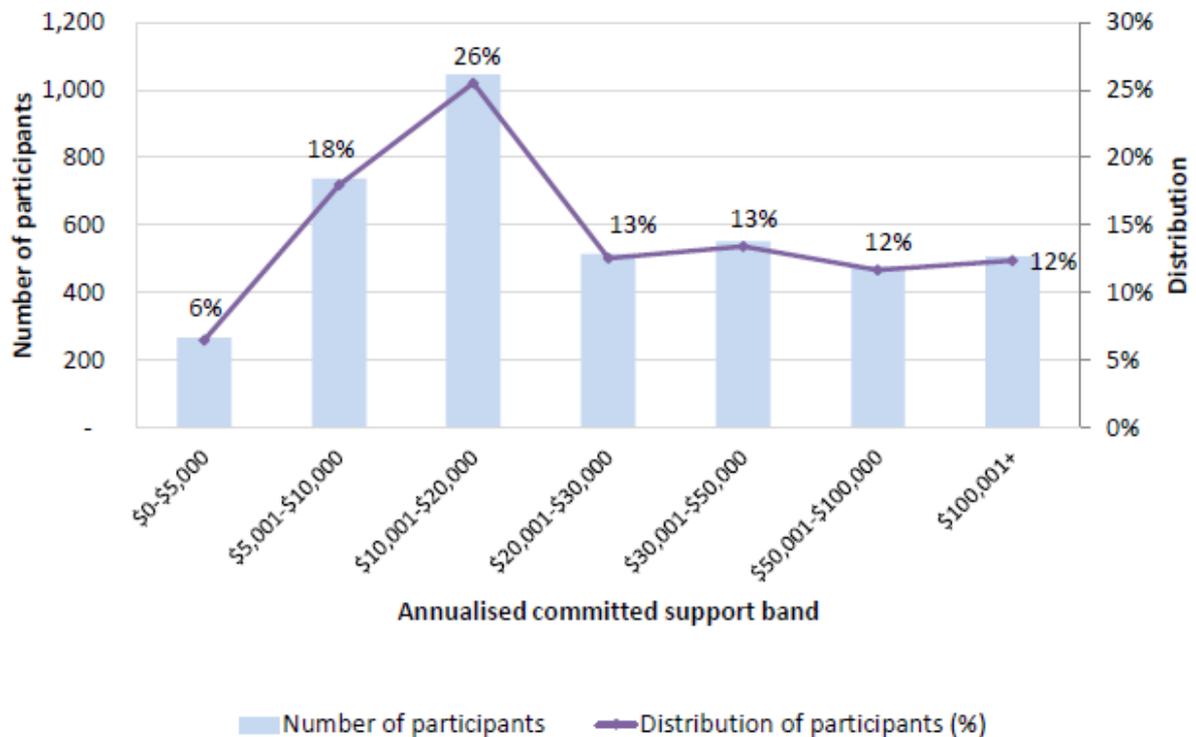
	ACT 30 June 2016	ACT 31 Dec 2016	Australia 30 June 2016	Australia 31 Dec 2016
Total (number)	6,390	7,079	41,523	88,128
In progress	596 (9.3%)	145 (2.1%)	2,155 (5.2%)	4,541 (5.2%)
Eligible	5,149 (80.6%)	5,998 (84.7%)	35,076 (84.5%)	76,269 (86.5%)
Closed	73 (1.1%)	47 (0.7%)	539 (1.3%)	454 (0.5%)
Revoked	7 (0.1%)	24 (0.3%)	77 (0.2%)	151 (0.2%)
Ineligible	437 (6.8%)	752 (10.6%)	2,823 (6.8%)	4,834 (5.5%)
Withdrawn	128 (2.0%)	113 (1.6%)	853 (2.1%)	1,879 (2.1%)

Source: (National Disability Insurance Agency, 2016f, National Disability Insurance Agency, 2017c)

In the second quarter of 2015-16, 50% of ACT participants with approved plans received support within 180 days of submitting an access request, similar to the national rate of 47% and down from the previous quarter (60%) (National Disability Insurance Agency, 2016f).

The average annualised plan amount in the ACT was \$47,992 at 30 June 2016, while the median annualised plan amount was \$20,082. As seen in Figure 1, about a quarter (26%) of participant plans were between \$10,001 and \$20,000.

Figure 1: Approved current plans for participants by cost band in the ACT, 30 June 2016



Source: (National Disability Insurance Agency, 2016d)

Assistance with daily living is by far the highest funded category in the ACT (\$172.9 million), with improved daily living skills second at \$42.5 million (Table 3) (National Disability Insurance Agency, 2016d). A total of \$269.7 million was committed to the 4,098 ACT participants with approved plans at 30 June 2016.

Table 3: Total amount committed to the 4,098 participants in the ACT for plans approved to 30 June 2016.

Support Category	Total Committed
Assistance with daily life at home, in the community, education and at work (includes supported independent Living)	\$172,931,024
Improved daily living skills	\$43,491,109
Improved life choices	\$13,519,635
Increased social and community participation	\$10,396,042
Transport to access daily activities	\$8,126,783
Assistive technology	\$6,722,848
Finding and keeping a job	\$4,366,852
Improved health and wellbeing	\$2,757,328
Improved relationships	\$2,527,002
Improved learning	\$2,177,291
Home modifications	\$1,011,966
Improved living arrangements	\$823,546
Assistance with daily life at home, in the community, education and at work	\$746,245
Vehicle modifications	\$134,911
Total	\$269,732,581

Note: a new support catalogue has been introduced by the NDIS to encourage outcome-focused support provision. The above categories reflect the new support catalogue and past supports have been mapped to the new catalogue.

Source: (National Disability Insurance Agency, 2016d)

Support to transition to the NDIS

There is a transition timetable which describes the phases for the ACT rollout. In the ACT, people started accessing the Scheme based on an "ages and stages" approach (as described on p.6). Current providers were asked to provide information about their clients to the NDIA, including their name, date of birth and details of disability. This was to ensure a smooth transition into the Scheme and to prevent clients needing to go over this information again when they first met with the NDIA.

NDIS transition for children

All school age children in the ACT were due to transition to the NDIS during January-September 2015, however, not all school aged children transitioned during this time. In August 2016, approximately 70% of children accessing ACT Education Directorate disability services had transitioned into the NDIS (Laurent, 2016). Some of the reasons for families not transitioning include:

- Feel their needs are already being met
- Don't see a need for applying
- Don't view the scheme as relevant to them, e.g. their child doesn't have a 'disability'
- Not aware of additional services that could be available to them through the NDIS (e.g. respite)
- Overwhelming or stressful (e.g. the paperwork and process)
- Don't feel that they have sufficient evidence of disability. They think they need a GP or paediatrician letter, but they can actually just reference the Education Directorate on the form and the NDIA will follow up with them
- They are waiting for the 'trial' to finish
- Misinformation – e.g. they think they will lose Centrelink entitlements
- Scared of data sharing
- Mistrust in the Government

Even when children are approved, parents/guardians may find it overwhelming to begin using their funding and choosing their own services, therefore they may not be using their plan and the money allocated to them.

Other issues associated with children and the NDIS have been identified through consultation. Of particular concern is the delay in accessing a plan, at a critical time in a child's development. Long delays have been seen with access requests (being deemed eligible) and then having a plan approved. In the third quarter of 2015-16 only 20% of ACT plans were approved within 90 days of an access request being submitted (National Disability Insurance Agency, 2016f). Gaps have also been identified between who is responsible for particular services (NDIS or Health Directorate), e.g. children who need to travel to Sydney for surgery (as it isn't available in Canberra) and once they return, those responsible for their care is complex. There are however advantages seen by the introduction of the NDIS and breaking down cross border issues and the ACT now having the ability to share equipment across the border with NSW.

There are some services that have taken longer than others to transition to being run through the NDIS, rather than the Education Directorate, these include special needs transport and personal needs in school (e.g. assistance peg-feeding, toileting, hygiene). Delays were also seen with the non-Government sector schools (i.e. Catholic and Independent schools) being involved in working groups, so they are trailing behind in taking on services, e.g. lack in transport.

NDIS and older people

One of the eligibility criteria of the NDIS is that the applicant is aged under 65 years when their access request is received by the NDIS. The requirement to be under 65 years of age to become a NDIS participant recognises that the NDIS is part of a broader system of support in Australia, with the intention that people over 65 should access the aged care system.

The need for clear processes and protocols for transition between the NDIS and the aged care system was highlighted during consultation. Clear pathways for collaborating with *My Aged Care* and NDIS-funded services was identified as a gap for hospitals, GPs, and other health professionals. Specifically highlighted was the potential for many older people to ‘fall through the cracks’ if clear provider roles and pathways were not established or communicated.

Aboriginal and Torres Strait Islander people with disability and the NDIS

Aboriginal and Torres Strait Islander Australians are at greater risk of disability. This is associated with poorer physical and mental health as well as increased exposure to risk factors and higher levels of socio-economic disadvantage (Australian Indigenous HealthInfoNet, 2016).

In 2012-13, 36% of Aboriginal and Torres Strait Islanders (an estimated 228,000 people) had some form of disability (Australian Institute of Health and Welfare, 2015). The prevalence of disability increased with age, ranging from 19% for those aged 0-14 years, to 67% for those aged 55 years and over. Approximately 6% of Aboriginal and Torres Strait Islander people (an estimated 41,000 people) had a severe or profound disability (Australian Institute of Health and Welfare, 2015). Aboriginal and Torres Strait Islander Australians were twice as likely as non-Indigenous Australians to have severe or profound disability (based on age-standardised rates) (Australian Institute of Health and Welfare, 2015). In 2012-13, the most common disability types among Aboriginal and Torres Strait Islander people with severe or profound disability were: physical disability (70%); and sight, hearing or speech related disability (53%) (Australian Institute of Health and Welfare, 2015).

The AIHW (2013) found that the ACT had a higher proportion of Aboriginal and Torres Strait Islander persons aged 18 years and over with a profound or severe core activity limitation, when compared to national rates. Aboriginal and Torres Strait Islanders aged 18 years and over in the ACT were 1.5 times as likely as non-Indigenous people in the ACT to have a disability or a long-term health condition in 2008 (Australian Institute of Health and Welfare, 2013).

In 2009-10, Aboriginal and Torres Strait Islander people in the ACT aged under 65 years used disability support services at a much lower rate than non-Indigenous people (2 compared with 35

per 1,000 population). Conversely, Aboriginal and Torres Strait Islander people at the national level used disability services at a much higher rate than non-Indigenous people (28 compared with 13 per 1,000) (Australian Institute of Health and Welfare, 2013).

Socio-economic disadvantage, marginalisation and a lack of culturally appropriate services are major barriers inhibiting many Aboriginal and Torres Strait Islander people from accessing the services and supports available to them and exercising their consumer rights effectively (Australian Indigenous HealthInfoNet, 2015). Like some non-Indigenous Australians, some Aboriginal and Torres Strait Islanders believe the NDIS is not relevant to them and/or their children as they don't perceive as having a 'disability'. The reluctance of Aboriginal and Torres Strait Islander people with disabilities to identify as people with disability remains little understood. This preference to not identify presents a fundamental barrier for the successful implementation of the NDIS (First Peoples Disability Network Australia, 2016).

The NDIA released an Aboriginal and Torres Strait Islander Engagement Strategy in March 2017 (National Disability Insurance Agency, 2017a). This reflects the different needs of Aboriginal and Torres Strait Islander people with disability and it recognises the need for different approaches when engaging with Aboriginal and Torres Strait Islander people and focuses on strengthening practical engagement activities to facilitate delivery of the NDIS for all Australians. The NDIA commits to train all staff to understand and engage with Aboriginal and Torres Strait Islander people and communities in a way that demonstrates respect and support for Aboriginal language, heritage and culture in the 'proper way' (National Disability Insurance Agency, 2017a).

At 31 December 2016, there were 240 Aboriginal and Torres Strait Islander people in the ACT who had approved NDIS plans, equating to 4.3% of the total ACT participants with an approved plan (National Disability Insurance Agency, 2017c).

Gugan Gulwan Youth Aboriginal Centre in the ACT provides an NDIS outreach service which promotes understanding and awareness about the NDIS among Aboriginal and Torres Strait Islander people in the ACT community (Gugan Gulwan Youth Aboriginal Corporation, 2017). The service provides information, facilitates community gatherings and conversations, offers practical assistance, supports people to develop whole of life and support plans and offers support for clients to complete NDIA forms and attend assessment and planning meetings with the NDIA.

Disability support services for Aboriginal and Torres Strait Islander people is a current priority for ACT's Winnunga Nimmityjah Aboriginal Health Service (Winnunga AHS) (Winnunga Nimmityjah Aboriginal Health Service, 2016). The ACT Government has committed to new infrastructure to

service Aboriginal health and community services, but there is no indication of whether this will include disability services. Winnunga AHS (in their 2017/18 ACT Budget Submission) highlighted that a large proportion of Aboriginal and Torres Strait Islander people with disability are likely to be existing Winnunga AHS clients and they would be able to provide disability support in a trusted and culturally safe environment (Winnunga Nimmityjah Aboriginal Health Service, 2016).

Culturally and linguistically diverse (CALD) people with disability and the NDIS

People from culturally and linguistically diverse (CALD) backgrounds with disability and their families experience multiple and complex layers of disadvantage and low levels of participation in mainstream and specialist disability services (AMPARO Advocacy Inc, 2016). A recent Australian study found that while the rate of disability was similar for those born overseas as to those born in Australia, there was a considerable gap in specialist disability services between people from CALD backgrounds and the broader community and this could not be explained by the difference in the level of need for assistance between Australian-born and overseas-born populations (Zhou, 2016). Highlighting there are barriers to the use of such services and the need to reduce the service access gaps to improve utilisation rates.

At 30 June 2016, there were 281 CALD ACT residents that were participants of the NDIS, equating to 6.9% of the total ACT participants (National Disability Insurance Agency, 2016f). Consultation suggested that services in the ACT are difficult to navigate, particularly for those from a CALD background. There are also issues surrounding the need for accessible (availability and cost) translation services for people with disability in the ACT. The NDIS website lists information in 10 languages other than English, however, this does not cover all languages spoken in Australia. It is also of concern that many people who do have a good understanding of the English language are struggling to understand the information provided and struggle to locate the answers to their questions.

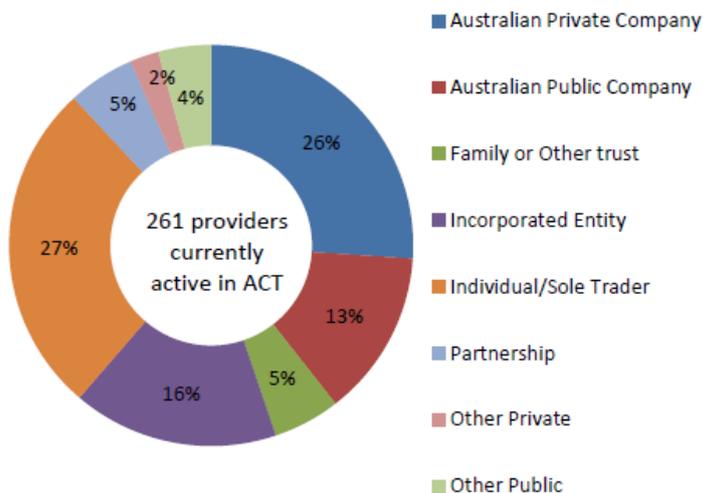
System issues

The non-government sector peak body, National Disability Services (NDS), recently released a report on the State of the Disability Sector (National Disability Services, 2016). They found demand for services was increasing as the NDIS was rolled out and almost 40% of service providers reported they could not meet demand, with one in five believing the clients they turned away would receive no service at all. Consultation has found that many NDIS participants are facing long waiting lists to see providers and are struggling to access services that are allocated to them in their plan.

NDIS registered providers

At 30 June 2016 there were 261 active providers in the ACT, with the majority being individual/sole traders (27%) or an Australian private company (26%) (Figure 2) (National Disability Insurance Agency, 2016d).

Figure 2: Type of approved NDIS registered providers in the ACT, 30 June 2016



Source: (National Disability Insurance Agency, 2016d)

Providers are able to offer a range of different supports and the number of providers approved to provide these supports in the ACT are listed in Table 4 (National Disability Insurance Agency, 2016d). The most common support offered was therapeutic supports, available through 83 providers. Therapeutic supports assist the participant to gain skills and improve independence related to identified needs. These include areas such as language and communication, personal care, mobility and movement, community living to support positive changes in the person's functioning, development and wellbeing. Therapeutic supports are delivered by professionals including Occupational Therapy, Physiotherapy, Speech and Language Pathology and Psychology or by a therapy assistant under the supervision of the therapist.

Table 4: Number of active NDIS providers approved to provide this support cluster with registered support items in the ACT, 30 June 2016

	# providers		# providers
Therapeutic Supports	83	Accommodation/Tenancy	27
Assess-Skill, Ability, Needs	65	Physical Wellbeing	27
Assist-Life Stage, Transition	58	Plan Management	20
Participate Community	54	Assist Prod-Pers Care/Safety	15
Early Childhood Supports	53	Personal Mobility Equipment	15
Development-Life Skills	46	Home Modification	12
Assist-Personal Activities	44	Other Innovative Supports	11
Assist-Travel/Transport	42	Comms & Info Equipment	10
Equipment Special Assess Setup	40	Assistive Equip-Recreation	9
Household Tasks	39	Assistive Prod-Household Task	9
Assist-Integrate School/Ed	34	Community Nursing Care	9
Behaviour Support	33	Interpret/Translate	6
Daily Tasks/Shared Living	32	Vision Equipment	6
Training-Travel Independence	32	Hearing Equipment	5
Assist Access/Maintain Employ	29		

Source: (National Disability Insurance Agency, 2016d)

Additional NDIS supports to be introduced in the ACT in 2017

Information, Linkages and Capacity Building (ILC)

Information, linkages and capacity building (ILC) has not been part of the NDIS trial period, however, it will begin in the ACT in July 2017 and contributes to the overall goal of the Scheme to enable people with disability to live an ordinary life. The focus of ILC will be community inclusion – making sure people with disability are connected into their communities and ensuring the community becomes more accessible and inclusive of people with disability (National Disability Insurance Agency, 2016b). This will be done via personal capacity building (ensuring people with disability and their families have the skills, resources and confidence they need to participate in the community or access the same kind of opportunities or services as other people), as well as community capacity building (ensuring mainstream services or organisations become more inclusive of people with disability).

Individuals are not funded under ILC, rather grants are provided to organisations to carry out activities in the community. Funded activities will build the capacity of mainstream services and community activities to be more inclusive and will benefit people with disabilities (including some activities for those who do not have an NDIS plan), as well as their families and carers.

The ACT recipients of the ILC grants were announced in April 2017 and the successful recipients are listed in Table 5. However, many services did not receive funding through the ILC grant process, consequently leaving gaps in services and supports available in the ACT. For example, TADACT, a not for profit organisation that specialises in creating or modifying equipment for people with disability, and Radio for the Blind, as well as other support groups and information channels, did not receive funding.

Table 5: Successful NDIS ILC Grants, ACT, 2017-18

Organisation	Summary of activity	Amount
ACT Deafness Resource Centre Inc.	The program is designed for those with hearing impairment to attend the ACT Deafness Resource Centre for one to one consultation to provide support, information, linkages and referrals and is accompanied by an annual Hearing Awareness Expo.	\$124,470
ACT Disability Aged and Carer Advocacy Service Inc.	Creating systemic change to ensure that the ACT Health Care System is more inclusive of people with impaired decision making ability.	\$322,638
ACT Playgroups Association Inc.	Developing an inclusion support program for community playgroups to enable young families with disabilities (either adult or child) to facilitate access to local community playgroups.	\$86,755
Advocacy for Inclusion Incorporated	Developing and delivering a justice orientation process to support individual people with disabilities to better understand and participate in their current justice process through self-advocacy skill building, and experiential learning techniques.	\$94,115
Clickability Proprietary Limited	Clickability Scale-Up – roll-out to the ACT in 2017 including delivery of community capacity building workshops on consumer rights for people with disability in the ACT.	\$150,000
Down Syndrome Australia	DSA will address the need for ongoing access to resources, peer support and quality information by leading a consortium of State and Territory Down syndrome Organisations to deliver the Information for Life project.	\$202,060
First People's Disability Network	This activity is to inform and educate Aboriginal and Torres Strait Islander people with disability and their families as well as the wider Aboriginal and Torres Strait Islander community in the ACT about what is meant by the term 'disability'. This will be delivered by utilising a peer to peer model led by Aboriginal people with disability who have disability and/or a close personal association with disability.	\$95,000
Imagine More Ltd	Supporting people with developmental disabilities and their families to live inclusive, typical and valued lives.	\$400,000
Koomarri	Establishing a peer support network of people with mild and borderline cognitive disability (not eligible for the NDIS) and their supporters who may be unemployed, socially isolated, at risk of criminal justice involvement and homelessness.	\$64,590
Multiple Sclerosis Limited	To be hosted on the MS Ltd website, Get Your ACT Together is being developed as an interactive tool that provides tailored, local advice for symptom management, so it suits exactly what people need on each occasion.	\$94,648
Rebus Theatre Incorporated	Open Doors Open Minds will be a series of interactive, disability-led capacity-building workshops for Community Organisations.	\$74,069

Organisation	Summary of activity	Amount
Self Help Organisations United Together Inc.	Development of a virtual support network, uniting support and self help groups across the ACT on a virtual platform, allowing them to have access to all the resources they may need, including support resources, policies, procedures, governance documentation and road maps to developing and maintaining a support structure.	\$123,000
The Deaf Society	Researching the barriers to accepting and seeking help for hearing loss. The research will inform the development of a progressive, impartial e-support service that includes an interactive website.	\$229,001
The Disability Trust	Presentation of a weekly radio segment on ACT commercial radio station 2CC, with information for and about people with a disability, their parents/ carers and families, disability support organisations and the wider community, and an integrated monthly newsletter.	\$71,598
Trustees of the Roman Catholic Church for the Archdiocese of Canberra & Goulburn	Marymead Autism Centre – providing a suite of strengths-based, person-centred services developed by experts for individuals/families living with Autism Spectrum Disorder including new diagnosis support, linkage/referral to other supports, and NDIS pre-planning support.	\$333,799
Trustees of the Roman Catholic Church for the Archdiocese of Canberra & Goulburn	Kids Companion Program - providing social support, mentoring, participant-driven peer-based activities and projects for young people with a disability (not on an NDIS plan), their siblings, and young people who care for someone with a disability (including psycho social disability).	\$157,000
Volunteering and Contact ACT Incorporated	Providing one-to-one support for people with a disability, in particular mental health consumers, to co-design an individualised support plan with a volunteer mentor.	\$200,000
Wellways Australia Limited	Training volunteers to work alongside people with psycho-social disability and assist them in building a strong network, increase community participation and to develop a sense of belonging within their community.	\$138,204
Arthritis Foundation of the ACT Inc.	Assisting people with arthritis to: better understand, manage and reduce the impact of their disability through access and utilisation of information and resources; developing relationships; confident decision-making; increasing targeted and mainstream community participation, toward a normal life. Participants will then form a cohort for ongoing support and connectedness.	\$9,900
Marymead Child and Family Centre	Delivery of the Autism Centre's Dungeons and Dragons - Virtual Life Training Group. Coordinated by a qualified teacher and a volunteer, participants will use their imagination, problem solve, and cooperate with others, developing skills and confidence enabling them to participate in, and contribute to, the community.	\$9,932
People with Disabilities ACT	Develop and disseminate information resources for people with disabilities in relation to mainstream services and the Commonwealth Disability Strategy including e-bulletin, website and social media.	\$9,800
Person Centred Support Pty Ltd	Disseminating information about disability, mainstream and community services at grass-roots level using targeted languages- Cantonese, Vietnamese and Arabic to inform and connect people with disability, their carers, guardians, family and friends from these CALD groups in ACT.	\$8,500

Local Area Coordination (LAC)

Local Area Coordination (LAC) services are an important part of the NDIS, as they will work with participants to help enter, and make the most of the NDIS (National Disability Insurance Agency, 2016b). They will also support individuals to build strong, inclusive relationships in the community and work with the local community to make sure it is welcoming and inclusive for people with disability (National Disability Insurance Agency, 2016a). Specifically, LAC can help people: understand the NDIS; access the NDIS; create a first plan; put the NDIS plan into action; and review the plan (National Disability Insurance Agency, 2016a). The successful service provider for LAC in the ACT is Feros Care and began providing services on 29th May 2017 in the ACT. There are currently approximately 20 Local Area Coordinators in the ACT working at a sub-regional level, with a final plan to have 45 LACs operating in the ACT (Marsh, 2017).

LAC will also provide information, linkages and basic capacity building supports to individuals in the community who do not have/do not want an NDIS plan. This includes assisting individuals to access community and/or mainstream services.

Early Childhood, Early Intervention (ECEI) approach

The Early Childhood, Early Intervention (ECEI) approach helps children (aged 0-6 years) with developmental delay and disability, and their families, to achieve better long-term outcomes through support services in their local community (National Disability Insurance Agency, 2016b). Providing children and families with timely, comprehensive and well-integrated early intervention support leads to better longer-term outcomes for children, encouraging inclusion and participation in their environment.

Families will meet with an ECEI partner to discuss their needs and the ECEI partner will draw on their specialised early childhood knowledge to support access to appropriate supports for the child and family (National Disability Insurance Agency, 2016b). This may include an assessment of the need for specialised early childhood intervention supports and children who require more intensive early intervention support will be referred to the NDIS. The NDIS will then determine the reasonable and necessary supports that will assist the child to achieve their desired outcomes and the family will be able to choose an appropriate provider to deliver the funded supports.

The successful service provider for ECEI in the ACT is EACH and began providing services in mid-2017.

Key Issues

Services that are out of scope for the NDIS

The interface between the NDIS and other disability and mainstream services is problematic. There is a lack of clarity in terms of where the responsibilities of different providers lie and who should be providing which services. Some people with a disability in the ACT have lost access to supports they used to get as disability services close down.

The Government asked the Productivity Commission to undertake an independent review into the overall costs of the scheme, its value for money and long-term sustainability. The full report is due by September 2017, however the Productivity Commission released a paper in June 2017 which highlighted a number of areas that are proving challenging for those accessing the scheme. One of these highlighted areas was the interface between the NDIS and other services. The report identified that some disability supports are not being provided because of unclear boundaries about the responsibilities of the different levels of government (Dickinson, 2017).

NDIS participants are likely to need healthcare services throughout their lives. Participants may also have more complex healthcare needs associated with their disability. Feedback during consultation has identified that many participants are confused about what is in scope for the NDIS, for example which system assists with rehabilitation, which assists with early intervention and what happens if the health system does not fund the supports they need. If the health system is responsible for a support, the NDIS cannot fund that support, even if the health system does not provide it (National Disability Insurance Agency, 2017a).

Psychosocial disability

Psychosocial disability is a term used to describe the experience of people with impairments and participation restrictions related to mental health conditions (Mental Health Australia, 2014). These impairments can include a loss of ability to function, think clearly, experience full physical health, and manage the social and emotional aspects of their lives. Those affected are prevented from engaging in opportunities such as education, training, cultural activities, and achieving their goals and aspirations. Not everyone with a mental illness will have a level of impairment that will result in a psychosocial disability, which effects someone's ability to participate fully in life as result of mental ill-health.

There is a strong focus on recovery in relation to mental ill-health as different levels of mental ill-health are variable and not permanent. However, in order to be eligible for the NDIS the participant needs to have a 'permanent impairment' or an impairment that is likely to be permanent.

Access to mental health care

Some people with mental health illnesses are falling through the cracks of the ACT's health system as existing services are dismantled to make way for the NDIS (Burdon, 2016). The NDIS is only taking the people with the most severe illnesses and there is still a large cohort of people with less severe, but permanent and episodic illnesses, who will be losing their existing community supports.

Some people have struggled to sign up to the NDIS, are too ill to do so or are ineligible, while some people are not signing up because of the perceived stigma attached to identifying themselves as having a permanent disability, or they don't recognise that they have an ongoing disability, much less an illness (Burdon, 2016).

Even once approved, an NDIS participant is only provided with limited and inconsistent 'plan coordination' time per month, but people with psychosocial illnesses often need more support during episodes of illness than available under their plans.

Consultation has found there are a lack of mental health providers available through the NDIS in the ACT, and long waiting lists to access the providers that have registered. Some psychologists have chosen not to register as NDIS providers, or have deregistered, mainly due to the pricing structure (i.e. they can charge non-NDIS clients more) and also the process involved. As a result, participants need to be self-managing their NDIS plan to be able to access these providers and need to pay for the consultation out of their own pocket before being reimbursed by the NDIS. Additionally, the provider may choose to charge more than the NDIS rate and in order to continue to see the provider the participant may have to pay an out-of-pocket cost or alternatively reduce the number of times they use the service so their plan can cover it in full.

Priority Issues

Need for education and support in relation to GP knowledge around the NDIS

Consultation has suggested GPs may not always be comfortable undertaking the NDIS access request assessment for a patient. This may be because they don't feel they have enough education or experience around the NDIS and its requirements or they do not know the specific impact the disability has on the patient's daily function. There is a perception in the community that a GP is required to complete the assessment form, however, other clinicians can complete the evidence

required on the NDIS forms (and may be more equipped to do this in regards to knowing the patient and the impacts on their daily function), however, this may increase the cost for the patient. If GPs (or specialists) are completing the assessment and are unable to describe the 'impact on daily function' sufficiently on a patients NDIS access request form, it may be deemed ineligible. As at 31 December 2016, 752 (10.6%) of NDIS access requests made in the ACT were deemed ineligible. Some of these may be due to insufficient 'impact on daily function' descriptions.

It is also important for GPs to be proactive in identifying the need for an NDIS application and also in completing access request forms, with delays seen in NDIS processing and approval time. Early identification and intervention in child development is particularly vital - any delay applying for an NDIS plan, along with the long time it takes once an access request form is submitted to when services begin, can be critical in child's development. Only 20% of ACT plans were approved within 90 days of an access request being submitted during the third quarter of 2015-16 (National Disability Insurance Agency, 2016f).

GPs also need to be aware about whether or not their patient has an active NDIS plan, and if it is self-managed (and a patient can see any provider) or if it is agency managed (and a patient can only see registered providers). It is therefore also important for GPs to be aware of who the NDIS registered providers are. The ACT has the highest rate of self-managed plans (15%) of all trial sites, and the second highest rate of combination managed plans (48%) and the lowest rate of agency managed plans (37%) (National Disability Insurance Agency, 2016f).

The support a GP can offer could play a big role in helping and supporting patients and families to navigate the NDIS system.

Strategy

Provide education and support to GPs in relation to the NDIS application process, plans, who the registered NDIS providers are and referral to LACs.

CHN has developed an NDIS HealthPathway.

People ineligible for or who chose not to transition to the NDIS

There are many people in the ACT who are not eligible for or who chose not to transition to the NDIS. People may be ineligible because of their age (i.e. over 65 years), or because of their visa status, or because they don't meet the disability or early intervention eligibility criteria. There are

also people who chose not to transition to the NDIS, for a range of reasons. While those aged over 65 years are eligible for My Aged Care services, all people with disability who aren't participating in the NDIS may not be able to access the services they require, some of which were available to them in the past. This has implications for the health system and may mean some people are not able to access mental health care and other services, which may lead to people presenting to ED because they can't afford, or can't access the care they require.

At 31 December 2016, the ACT had the highest rate of ineligible NDIS applications at 10.6% (National Disability Insurance Agency, 2017c). If a person is deemed ineligible for the NDIS there is a degree of suffering and stress involved. If it was due to an insufficient description of impact on daily function, it might take quite a while for the individual to gain the confidence to apply again. Clinicians also feel frustrated after putting time and effort into completing the form and it being declined.

Health workers and consumers need the knowledge and support about what services are available to those people who aren't participants of the NDIS. Vulnerable families may have a high level of association with the health system and with Care and Protection Services, so these services (including GPs) could help in this space.

Strategy

Support and educate GPs and other primary health care providers about services available for those who aren't NDIS participants, but still need to access services.

Access to allied health services

Allied health services in the ACT are experiencing high demand and long waiting lists. There are limited NDIS registered services for some domains in the ACT (e.g. physiotherapy, psychologists, speech pathology, OT) and this is causing frustration and likely having impacts on people's health. Some allied health providers aren't registering as NDIS providers as they believe they would be financially worse off. Some providers are deregistering, allegedly because of the loss of potential income and the undesirable processes that come with the NDIS.

The cost of appointments and also physically getting to allied health providers (including transport) are also other access issues faced by people with a disability.

Strategy

Collaborate with NDIS and professional associations on examining the options for increasing allied health service supply.

Child development and early intervention

Many children in the ACT require support for optimal child development. Speech (language and communication) is the most common reason children require assistance at the ACT Child Development Service (Jordaan, 2016). Providing children with timely, comprehensive and well-integrated early intervention support leads to better longer-term outcomes for children, encouraging inclusion and participation in their environment.

Many of the challenging behaviours exhibited by students at school have a much longer history, often developing in early childhood, before starting school (Shaddock et al., 2015). To minimise the negative impact of these issues on children's behaviour and development, appropriate interventions must start as early as possible (e.g. at the time of their recognition or diagnosis) (Shaddock et al., 2015). Supports offered should be tailored to meet the individual needs of children and should be available early, when help is most likely to be beneficial.

It can be very difficult to target vulnerable children and get them to transition to the NDIS. There are many reasons why families are not transitioning to the NDIS, however, it is important for these families to be aware of the benefits of becoming a participant of the NDIS, and children should be identified, and assisted through the process of applying, by primary health care providers.

Strategy

Support and educate GPs about available resources/services in relation to the NDIS.

Provide educational opportunities for focusing on vulnerable children and the ways in which GPs can support families and identify and refer children to appropriate services.

Continuous development and promotion of paediatric HealthPathways to assist GPs with assessment, management and referrals.

Child and adolescent mental health (also see Mental Health chapter)

Mental disorders in children can impact on their functioning at school, with family and friends and in their community. Data suggests that the prevalence of mental disorders in Australian young people and their use of services for these problems has significantly increased between 1998 and 2013-14 (Lawrence et al., 2015). In 2013-14, almost one in seven (13.9%) 4-17 year olds were assessed as having mental health disorders in the previous 12 months, equivalent to 560,000 Australian children and adolescents. Males were more likely than females to have experienced mental health disorders in the previous 12 months (16.3% compared to 11.5%). The most common mental disorder was ADHD (7.4%), followed by anxiety disorders (6.9%), major depressive disorder (2.8%) and conduct disorder (2.1%) (Lawrence et al., 2015). Approximately one third (30%) of children and adolescents with a disorder had two or more mental disorders at some time in the previous 12 months.

Adolescents (12-17 years) with a mental disorder were almost three times more likely to experience a severe mental disorder (23%) than 4-11 year olds (8.2%) with a mental disorder (Lawrence et al., 2015). Nearly four fifths (78.6%) of 4-17 year olds with mental disorders were reported as needing help in the previous 12 months, however, for a quarter (26.2%) of these children and adolescents these needs were not met. The met need increased with severity of the disorder, with 84.2% of those with severe disorders and 81.8% of those with moderate disorders having their needs for help fully or partially met (Lawrence et al., 2015).

It has been recognised by the ACT government that identification and access to early intervention services around developmental delay and mental health is complex and difficult to navigate for consumers. The introduction of the NDIS and the reduction of services provided by the Child Development Service (formerly Therapy ACT) has contributed to this complexity.

Distinguishing between transient behaviours and early mental health problems can be difficult (Campbell, 2006). Behaviours that are frequent and transient in most young children can also indicate more serious problems that may merit mental health intervention. Therefore primary/universal service providers (e.g. GPs, community nurses, child care providers, early childhood educators/teachers) should always explore any concerns that parents raise about their child's behaviour or emotional development. Referral for specialist intervention may be necessary when there is a cluster of persistent symptoms across settings or relationships, when symptom severity is likely to impede the child's ability to achieve developmental tasks, and where it affects day-to-day functioning (Campbell, 2006).

The incidence of mental health problems is even higher for those from disadvantaged backgrounds, including Aboriginal children (24%) (Zubrick et al., 2005), children residing in 'out of home care' (55-

60%) (Tarren-Sweeney and Hazell, 2006) and children with a learning disability, who are up to four times more likely to have mental health problems than children with no disability (Witt et al., 2003).

The younger the child, the more vulnerable their brain is to environmental influences. Experiences in the early years shape the development of young children's brains in ways that have long lasting effects. Mental health problems can develop at any stage of life, including infancy and pre-school age. Good mental health is essential for children's learning, social development, self-esteem and resilience to stress (Royal Children's Hospital, 2006). The best chance of preventing mental disorders or providing early intervention to minimise the impact of mental illness across the lifetime is during childhood. Untreated conduct disorders in childhood significantly increase the social and economic costs to the individual and the community later in life. Childhood mental health problems often continue into adolescence and then adulthood, adding further costs related to areas such as school dropout, substance abuse, poor employment outcomes, family violence and suicide, along with sick leave, unemployment and crime (Royal Children's Hospital, 2006). This can then affect the next generation of children.

The effectiveness of early intervention is poorly recognised in the current system and schools and early childhood services are generally ill-equipped to identify problems early and intervene effectively. Additionally, the child mental health services in Australia that do exist can struggle to bridge the gaps between health and the settings where children spend much of their time – education or child care (Department of Health, 2011).

Only twenty-five per cent of young people with mental illness access services, and for most there is a long delay between the start of symptoms and when they receive help (Department of Health, 2011). Young people are hard to reach, as they don't necessarily make regular visits to health services.

Government funding for initiatives such as Better Access, headspace and suicide prevention has had some success, but young Australians still need better access to more services to minimise the toll of mental illness on their lives and their families.

Please refer to the mental health section for more information about access to early mental health intervention services.

Strategy

See Mental health chapter.

References

- ACT COMMUNITY SERVICES. 2016. *NDIS FAQ* [Online]. Canberra: ACT Government. Available: http://www.communityservices.act.gov.au/disability_act/national_disability_insurance_scheme/faq-individuals [Accessed 1 Aug 2016].
- AMPARO ADVOCACY INC 2016. The NDIS and Culturally and Linguistically Diverse Communities: Aiming high for equitable access in Queensland. AMPARO Advocacy Inc.
- AUSTRALIAN BUREAU OF STATISTICS. 2011. *Disability, Australia, 2009. Cat. no. 4446.0* [Online]. Canberra: ABS. Available: <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4446.0main+features22009> [Accessed 1 Aug 2016].
- AUSTRALIAN BUREAU OF STATISTICS 2013. *Disability, Ageing and Carers, Australia: Summary of Findings, 2012. Cat. no. 4430.0.* Canberra: ABS.
- AUSTRALIAN BUREAU OF STATISTICS 2016. *Disability, Ageing and Carers, Australia: Summary of Findings, 2015. Cat. no. 4430.0.* Canberra: ABS.
- AUSTRALIAN INDIGENOUS HEALTHINFONET. 2015. *Disability within the Indigenous community* [Online]. Australian Indigenous HealthInfoNet. Available: <http://www.healthinfonet.ecu.edu.au/related-issues/disability/reviews/disability-within-the-indigenous-community> [Accessed 5 Jan 2017].
- AUSTRALIAN INDIGENOUS HEALTHINFONET 2016. Overview of Australian Indigenous and Torres Strait Islander health status, 2015. Perth, WA: Australian Indigenous HealthInfoNet.
- AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE 2013. *Aboriginal and Torres Strait Islander Health Performance Framework 2012 report: Australian Capital Territory. Cat. no. IHW 96.* Canberra: AIHW.
- AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE 2015. *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015. Cat. no. IHW 147.* Canberra: AIHW.
- AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE 2016. *Health status and risk factors of Australians with disability 2007–08 and 2011–12. Cat. no. DIS 65.* Canberra: AIHW.
- AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE 2017. *Life expectancy and disability in Australia: expected years living with and without disability. Cat. no. DIS 66.* Canberra: AIHW.
- AUSTRALIAN NETWORK ON DISABILITY. 2016. *What is a disability?* [Online]. Sydney: AND. Available: <http://www.and.org.au/pages/what-is-a-disability.html> [Accessed 22 Aug 2016].
- BURDON, D. 2016. *Canberrans fall through the cracks between NDIS and older support services. Canberra Times, 21 Oct 2016.*
- CAMPBELL, S. B. 2006. *Maladjustment in preschool children: A developmental psychopathology perspective. Ch. 18. In: MCCARTNEY, K. & PHILLIPS, D. (eds.) Blackwell Handbook of Early Childhood Development. Oxford, UK: Blackwell Publishers.*
- DEPARTMENT OF HEALTH. 2011. *Early intervention and prevention, and mental health services for children and young people* [Online]. Commonwealth of Australia. Available: <http://www.health.gov.au/internet/publications/publishing.nsf/Content/nmhr11-12~nmhr11-12-challenges~earlyintervention> [Accessed 15 Sept 2016].
- DICKINSON, H. 2017. *The NDIS costs are on track, but that doesn't mean all participants are getting the support they need. The Conversation, 15 June.*
- FIRST PEOPLES DISABILITY NETWORK AUSTRALIA. 2016. *Ten-point plan for the implementation of the NDIS in Aboriginal and Torres Strait Islander Communities* [Online]. First Peoples Disability Network Australia. Available: <http://fpdn.org.au/ten-point-plan-for-the-implementation-of-the-ndis-in-aboriginal-communities/> [Accessed 5 Jan 2017].
- GORREY, M. 2016. *Autism Asperger ACT merger with Marymead prompted by NDIS funding limbo. Canberra Times, 1 Aug 2016.*

- GUGAN GULWAN YOUTH ABORIGINAL CORPORATION. 2017. *Services* [Online]. Gugan Gulwan Youth Aboriginal Corporation. Available: <http://www.gugan-gulwan.com.au/services> [Accessed 27 Jan 2017].
- JORDAAN, E. 8 Sept 2016 2016. *RE: Personal Communication*.
- LAURENT, K. 1 Sept 2016 2016. *RE: Personal Communication*.
- LAWRENCE, D., JOHNSON, S., HAFEKOST, J., BOTERHOVEN DE HAAN, K., SAWYER, M., AINLEY, J. & ZUBRICK, S. 2015. *The Mental Health of Children and Adolescents. Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing*. Canberra: Department of Health.
- MARSH, G. 19 June 2017. *RE: Personal Communication*.
- MENTAL HEALTH AUSTRALIA. 2014. *Getting the NDIS right for people with psychosocial disability* [Online]. Available: <https://mhaustralia.org/general/getting-ndis-right-people-psychosocial-disability> [Accessed 13 Jan 2017].
- NATIONAL DISABILITY INSURANCE AGENCY. 2016a. *Local Area Coordination* [Online]. NDIA. Available: <https://www.ndis.gov.au/communities/local-area-coordination> [Accessed 6 Jan 2017].
- NATIONAL DISABILITY INSURANCE AGENCY 2016b. *Market Position Statement Australian Capital Territory with Southern New South Wales region*. September 2016. NDIA.
- NATIONAL DISABILITY INSURANCE AGENCY. 2016c. *NDIS in the ACT* [Online]. Available: <https://myplace.ndis.gov.au/ndisstorefront/about-us/our-sites/act.html> [Accessed 1 Aug 2016].
- NATIONAL DISABILITY INSURANCE AGENCY 2016d. *NDIS market analysis dashboard ACT 30 June 2016*. NDIS.
- NATIONAL DISABILITY INSURANCE AGENCY. 2016e. *NDIS: Our history* [Online]. NDIA. Available: <https://www.ndis.gov.au/about-us/our-history> [Accessed 21 June 2017].
- NATIONAL DISABILITY INSURANCE AGENCY 2016f. *Quarterly Report to COAG Disability Reform Council 30 June 2016*. NDIA.
- NATIONAL DISABILITY INSURANCE AGENCY 2017a. *Aboriginal and Torres Strait Islander Engagement Strategy*. NDIA.
- NATIONAL DISABILITY INSURANCE AGENCY 2017b. *ACT Public Dashboard: 31 December 2016*. NDIA.
- NATIONAL DISABILITY INSURANCE AGENCY 2017c. *Quarterly Report to COAG Disability Reform Council 31 Dec 2016*. NDIA.
- NATIONAL DISABILITY INSURANCE SCHEME 2016. *Participating in the NDIS in the ACT. Factsheet.: NDIS*.
- NATIONAL DISABILITY SERVICES 2016. *State of the Disability Sector Report 2016*. NDS.
- ROYAL CHILDREN'S HOSPITAL 2006. *Childhood mental health: promotion, prevention and early intervention. Policy Brief: Translating early childhood research evidence to inform policy and practice*. No 5. Melbourne: Centre for Community Child Health, Royal Children's Hospital.
- SHADDOCK, A., PACKER, S. & ROY, A. 2015. *Schools for all children & young people: Report of the expert panel on students with complex needs and challenging behaviour*. Canberra.
- TARREN-SWEENEY, M. & HAZELL, P. 2006. *Mental health of children in foster and kinship care in New South Wales, Australia. J Paediatr Child Health, 42, 89-97*.
- WINNUNGA NIMMITYJAH ABORIGINAL HEALTH SERVICE 2016. *2017-18 ACT Budget Submission: Planning and Delivering Services to Address the Entrenched Disadvantage in the ACT Aboriginal and Torres Strait Islander Community*. Canberra: Winnunga Nimmityjah.
- WITT, W. P., RILEY, A. W. & COIRO, M. J. 2003. *Childhood functional status, family stressors, and psychosocial adjustment among school-aged children with disabilities in the United States. Archives of Pediatrics & Adolescent Medicine, 157, 687-695*.
- ZHOU, Q. 2016. *Accessing disability services by people from culturally and linguistically diverse backgrounds in Australia. Disability and Rehabilitation, 38, 844-52*.

ZUBRICK, S., SILBURN, S., LAWRENCE, D., MITROU, F., DALBY, R., BLAIR, E., GRIFFIN, J., MILROY, H., DE MAIO, J., COX, A. & LI, J. 2005. The Western Australian Aboriginal Child Health Survey: The Social and Emotional Wellbeing of Aboriginal Children and Young People. Perth: Curtin University of Technology and Telethon Institute for Child Health Research.