Way forward to inclusive service system:

Challenges for people with disability with closure of ADHC

April 2018



About NCOSS

The NSW Council of Social Service (NCOSS) works with and for people experiencing poverty and disadvantage in NSW to make positive change in our communities.

As the peak body for health and community services in NSW for over 80 years we support the sector to deliver crucial services that make a difference.

We work directly with communities to identify the challenges they face and solutions that will allow them to overcome those challenges.

Through collaboration with communities, services and across government, the private sector and other civil society organisations we work to see these solutions become a reality.

Together we advocate for a NSW free from poverty and inequality.

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NCOSS can be found at:

3/52 William St, WOOLLOOMOOLOO NSW 2011

phone: (02) 9211 2599 email: info@ncoss.org.au website: www.ncoss.org.au facebook: on.fb.me/ncoss

twitter: @ ncoss



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Introduction

From 30 June 2018, NSW will no longer have a dedicated Minister or Department responsible for disability issues.

In addition to direct service provision, the Department of Ageing and Disability Home Care (ADHC) had taken on the responsibility of mainstream service systems that had been unable to provide the support required by some people with complex disability. Thus, the closure of ADHC will present challenges for Departments across Government, which must build their capacity to be inclusive.

Both the National Disability Strategy¹ and the COAG principles determining the relationship between the NDIS and mainstream system (interface principles)² emphasise that all Governments have a role to play in achieving an inclusive society for people with disability. Accordingly, the responsibility for filling gaps created by ADHC's closure rests across the NSW Government. The Productivity Commission confirms that State Governments should only withdraw their support services once continuity of support arrangements between jurisdictions is clarified. ³

We know that people with disability face poor life outcomes in many areas. Throughout their lives, they are more likely to:

- be removed from their families for want of effective support;
- be excluded or segregated at school;
- be denied safe housing appropriate to their needs;
- be over represented in prison; and
- die preventable deaths due to an unresponsive healthcare system.

These are not the markers of an inclusive society mandated by the Disability Inclusion Act 2014.

Whilst progress has been made on these issues, a whole of Government response is critical to ensure progress is maintained and outcomes do not worsen. A NSW Government lead agency on disability is required.

Drawing on the expertise and work of our members, this report analyses the challenges of creating an inclusive society without a Department dedicated to disability. We outline the impact of these gaps, many of which are already being felt, and recommend actions to increase responsiveness of the service system. In relation to services provided by ADHC to children aged 0-6, we endorse the report and recommendations of our member Early Children Intervention Australia (ECIA).⁴

The gaps created by the closure of ADHC cannot be filled by the National Disability Insurance Scheme (NDIS), which by legislation is prevented from providing support that 'is more appropriately funded or provided through



¹ Council of Australian Governments National Disability Strategy 2010-2020.

² Council of Australian Governments (2015) <u>Principles to determine the responsibilities of the NDIS and other service systems.</u>

³ Productivity Commission (2017), National Disability Insurance Scheme (NDIS) Costs, at 2.

⁴ Early Children Intervention Australia (2018) Gaps in Services Age 0-6 with Developmental Delay and Disability.

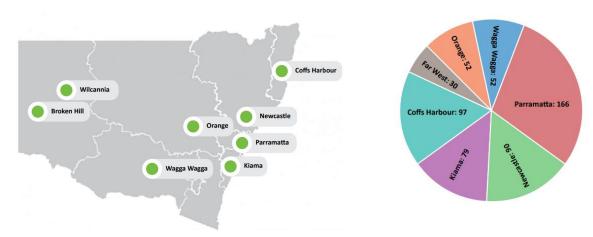
other general systems of service delivery ... as part of a universal service obligation or in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.⁵

Our members have emphasised ways in which the NDIS has failed to meet the needs of people supported by their services. While acknowledging the continued evolution of the NDIS, we present these issues as an Appendix to inform emerging policy and identify areas in need of adjustment. Where an issue concerns both the NSW Government and the National Disability Insurance Agency, it is covered in both the report and the Appendix.

This report also highlights the crucial work of independent disability advocacy, information and representation organisations across all areas of Government. While we commend the Government on its recent commitment to two years of additional funding to these organisations, ongoing funding is needed to ensure people with disability have assistance to navigate mainstream systems, and that these mainstream systems continue to become more accessible and inclusive. Advocacy organisations provide the Government with crucial partners in the implementation of its responsibilities to people with disability under the *Inclusion Act 2013*.

We further urge the NSW Government to appoint a Minister for Disability Services in the Cabinet to ensure proper oversight is provided to issues affecting people with disability, and that NSW continues to be an inclusive society.

Methodology



This report was informed by:

 NCOSS Regional Consultations: in 2017, NCOSS conducted consultations at 7 regional locations across NSW (see map above). At each consultation, we asked our members and stakeholders about priority areas including disability, to gain insights into regional challenges and solutions. The challenges experienced by people with disability in terms of accessing mainstream services was a consistent theme of the consultations. The crucial role played by independent advocacy and information services in

https://www.nsw.gov.au/your-government/the-premier/media-releases-from-the-premier/up-to-26-million-for-advocacy-groups/



⁵ National Disability Insurance Act (2013) s 34(f)

- assisting people with disability to navigate these gaps was the strongest message of the consultations and became one of our 2018/19 Pre-Budget Submission recommendations. ⁷
- Member Roundtables: NCOSS held a series of roundtables with our members to have a deeper
 conversation about the challenges faced by people with disability in relation to particular areas of
 mainstream services. Members were invited to contribute their knowledge, expertise and previous work
 and share the experiences of the people with disability they assist. This report reflects the contribution
 of:
 - Ability Incorporated
 - Action for People With Disability
 - o Being: Mental Health & Wellbeing Consumer Advisory Group
 - Blind Citizens NSW
 - Carers NSW
 - Community Transport Organisation
 - Council for intellectual Disability NSW
 - o Deafness Council NSW
 - Early Childhood Intervention Australia NSW
 - o Family Advocacy
 - o Intellectual Disability Rights Service
 - Motor Neurone Disease Association of New South Wales
 - Multicultural Disability Advocacy Association
 - o People With Disability Australia
 - o Physical Disability Council
 - o Spinal Cord Injuries Australia
 - Uniting

⁷ NCOSS (2017) NCOSS Our <u>Pre-Budget Submission 2018/19</u>, A roadmap for a fair <u>NSW</u>, (at 21-22.) called for the maintenance of funding for disability advocacy and information organisations beyond June 30 2018.



Summary of recommendations for the NSW Government

Challenge	Impact	Recommendation	Responsibility
	Health		
Specialist services currently funded by ADHC have no reliable source of funding post June 2018.	Health discrepancies of people with intellectual disability may continue to worsen.	Create a state-wide network of intellectual disability health teams.	NSW Health
GPs will lack tools for assessing the health of people with intellectual disability.	 Be denied preventative healthcare and diagnosis; experience greater hospitalisation (inpatient and emergency); and die more preventable deaths. 	2. Provide ongoing funding to license GPs to provide Comprehensive Health Assessment Program.	NSW Health
Health system will lose research capability and expertise in intellectual disability and mental health.	Progress in intellectual disability and mental health will stall. Local Health Districts will not be able to build their capacity in intellectual disability and mental health.	3. Fund the Chair of Intellectual Disability and Mental Health and 11 new traineeships in intellectual disability and mental health.	NSW Health
Uncertainty over responsibility and funding of eating and drinking management plans for people with dysphagia.	People with dysphagia will die preventable deaths from choking.	4. Interim recommendation: accept responsibility and fund assessments and the development of meal time plans.	NSW Health
People ineligible for NDIS will lose their disability support.	People will face challenges in daily living leading to increased hospitalisations and isolation.	5. Provide support to people previously accessing Community Care Support Program (CCSP) who are ineligible for the NDIS.	FACS

The health system lacks responsiveness to people with disability.	People with disability do not receive the health services they need.	 6. Implement <i>The Essentials</i> to enable Local Health Districts to map their capabilities and monitor their progress. 7. Develop accessible health information including in alternate formats such as braille and easy read. 	NSW Health
		8. Provide ongoing training of all health staff in disability awareness and competence, with an emphasis on appropriate communication.	
	Just	ice	
People charged will not be supported at police stations and in courts.	More people with disability will be imprisoned (without rehabilitation). Government will face increased adjournments and an increase of costs related to recidivism such as legal fees, court and custodial costs. Fewer people with cognitive disability will have access to diversionary options.	9. Fund a service similar to the Criminal Justice Support Network (CJSN). Additional funding should assure that this service is adequately resourced to support people with disability across NSW.	Department of Justice
People are not supported to secure diversionary orders.	Offenders with cognitive impairment are more likely to be sentenced and imprisoned due to lack of evidence to support a diversionary order.	10. Expand a remodelled Cognitive Impairment Diversion Program.	Department of Justice
Offenders with intellectual disability do not receive the holistic wraparound support they required.	Increased rates of victimisation, contact with police and courts, and imprisonment. Increased hospitalisation rates are likely.	11. Lead the development of specialist wrap-around services for offenders with cognitive disability.12. Existing Criminal Justice Project (CJP) providers to be given a lead role in supporting the growth.	FACS/ Premier and Cabinet

People with complex needs			
Lack of holistic wrap-around support for people with complex needs.	Poor outcomes for participants and additional costs to other areas of government.	13. Expand the Integrated Services Response to provide holistic support, and ensure staff are equipped with the knowledge skills and expertise required to provide this support.	Department of Justice
	Intensive far	mily support	
Vulnerable families of children with disability lack holistic support.	Increase in the number of children with disability in out of home care, through family relinquishment or forced removal.	14. Fund intensive family support programs for children with disability.	FACS
Parents with disability fear their child will be removed if they seek support for parenting.	Parents may not feel empowered to seek the support they need. The lack of support can put children at risk.	15. Provide support to parents with disability who are not NDIS participants to undertake their parenting roles.	FACS
Children with disability in voluntary out of home care may lose option of foster care.	Reduction in the number of foster carers for children with disability forcing those in out of home care to live in inappropriate group accommodation.	16. Recognise and compensate foster carers for the additional support they provide when a child has a disability.	FACS
	Trans	sport	
Less funding for community transport for people with disability.	People with disability miss out on important health appointments and other commitments and remain socially isolated. Increased demand for the transport disadvantage portion of funding.	 17. Significantly increase transport services and supports available to people with disability who are unable to use public transport and people experiencing transport disadvantage. Guidelines for the expanded funding pool should: retain previous CCSP eligibility criteria to ensure continuity of access; and 	Transport NSW
	Loss of community transport infrastructure as many transport providers go out of business.	 broaden eligibility criterion for community transport to clearly include transport disadvantage. 	

Housing			
Social housing			
Housing allocations do not target people with disability.	People with disability stay on waiting lists indefinitely.	 18. Introduce: allocations of social housing specifically targeted at people with disability; a NSW Affordable Disability Housing Strategy with a focus on accessibility; and equitable access to capacity to borrow for housing programs targeting housing for people with disability. 	FACS/Housing NSW
Housing allocations do not take sufficient account of disability requirements.	People are ineligible for priority housing if they have been living with family or living in shared supported accommodation. People are offered housing that is unsuitable for their access needs, despite specifying these on their application. This disadvantage is exacerbated by the requirement to inspect a property within 24 hours. The long wait times for repairs (including heating and cooling) make life difficult for people with disability who are less able to adjust their lifestyle. There are challenges to securing an additional bedroom at an affordable rent if required.	 People with disability living in unsustainable or restrictive situations are included in priority allocations; people who need a carer have access to an additional bedroom at an affordable rent as proposed in the National Disability Strategy; applicants are not disadvantaged by declining offer; transparent accessible information is available about available lettings and allocations criteria; support is available during bidding process; and repairs required by tenants with disability are prioritised. 	FACS/Housing NSW
Private rental market			T
The private rental market does not provide security of tenure.	People with disability have limited access to properties on the private rental market.	20. Amend the <i>Residential Tenancies Act 2010 (NSW)</i> to remove the capacity for no grounds evictions.	Minister For Housing

Home ownership			
NSW has no proactive measures to increase home ownership by people with disability.	Home ownership by people with disability is very low in NSW.	21. Develop a shared equity scheme targeted at people with disability.	Housing NSW
Accessible housing			
Supply of accessible housing does not meet demand.	Difficult to measure impact as data on accessible social housing is not available	22. Ensure that all FACS/ Housing NSW properties are built to Silver Liveable Housing Australia standard.	Housing NSW
		23. Continue to support minimum accessibility standards in the National Construction Code with the commitment to consult disabled persons and advocacy organisations in the Regulatory Impact Assessment process mid-2018.	
People with disability experience challenges in locating suitable properties.	People with disability are unable to locate properties with adaptable and accessible features.	24. Develop a central repository of information about adaptable and accessible housing.	Housing NSW
Planning regulations do not promote accessible, affordable housing.	Lack of accessible affordable housing.	25. Implement the recommendations of the Affordable Housing Working Group to enforce or encourage the development of affordable housing.	Planning NSW

Health

What is the problem?

People with disability, particularly intellectual disability, are likely to have more health problems than other people in the community, and these problems are likely to be severe and complex. However, these problems are less likely to be diagnosed and treated.

Compared to people without disability:

- people with intellectual disability are 2 to 3 times more likely to have a mental health condition.[^]
- people with severe or profound disability are more likely to have acquired a longterm health condition earlier.^^

People with disability face both physical and attitudinal barriers in accessing health care, and are rarely the target of health prevention and promotion activities. Critically, medical professionals are often inadequately trained to be aware of the needs of people with disability, including how to communicate appropriately.

We know that this can have devastating consequences. Research examining NSW Health records from 2005-2011 shows that people with intellectual disability died 27 years

younger than the general population, and 38% of deaths of people with intellectual disability were potentially avoidable. 8

ADHC provide a range of specialist and generalist supports to address the health needs of people with disability. Unless NSW Health steps in to provide these services, the discrepancy in health outcomes may worsen.

Specialist services funded by ADHC have no reliable source of funding post June 2018

ADHC currently funds a number of specialist services, including:9

- specialist health nurses who work with the clients of ADHC accommodation services, using their knowledge of the health needs of people with intellectual disability to promote a holistic approach to their health and wellbeing;
- nurses and dieticians in the dysphagia clinic at Westmead hospital who assist people with swallowing impairments;
- outreach psychiatry clinics in regional areas, giving people with intellectual disability access to assessments and reviews by experts in intellectual disability mental health; and
- a specialist medical clinic in Newcastle, where clinical nurse consultants coordinate medical specialists to assess and treat people with intellectual disability, providing multidisciplinary access to specialist care.

In addition, pilots of intellectual disability health teams operating in Northern Sydney and South Eastern Sydney



[^] Department of Developmental Disability Neuropsychiatry (2014). Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers. Department of Developmental Disability Neuropsychiatry, at 8.

^{^^} Australian Institute of Health and Welfare (2010) Health of Australians with disability; health status and risk factors, at 9

⁸ Troller, J et al, (2017) "Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data", BMJ Open, vol 2, issue 7.

⁹ Information sourced from the NSW Council of Intellectual Disability

Local Health Districts, and the Sydney Children's Hospital Network ¹⁰ have been effective in improving health outcomes for people with intellectual disability. ¹¹ These teams comprise of doctors, clinical nurse consultants and allied health professionals with expertise in health issues experienced by people with intellectual disability. The teams:

- perform a case co-ordination role, bringing together a range of health professions that a person with an intellectual disability may need to access; and
- provide advice, support and education to other health professionals working with people with intellectual disability.

Unless NSW Health funds these specialist services, health discrepancies of people with intellectual disability may continue to worsen.

Recommendation 1

NSW Health create a state-wide network of intellectual disability health teams, expanding on current pilots to provide either:

- a team in each Local Health District; or
- a team in large Local Health Districts with outreach roles to rural and remote areas including a network of clinical nurse consultants physically based in those areas.

GPs will lack tools for assessing the health of people with intellectual disability

ADHC funds licenses for the Comprehensive Health Assessment Program (CHAP) that gives GPs access to research validated tools to conduct health assessments for people with intellectual disability. CHAP guides the GP to health vulnerabilities which may be useful where there are communication barriers.

People with intellectual disability will:

- be denied preventative healthcare and diagnosis.
- experience greater hospitalisation (inpatient and emergency AND
- die more preventable deaths.

Recommendation 2

NSW Health provide ongoing funding to license GPs to provide Comprehensive Health Assessment Program.

Health system will lose research capability and expertise in intellectual disability and mental health

ADHC and NSW Health fund a Chair in Intellectual Disability and Mental Health until 2020 that provides

¹¹ KPMG (2009) Analysis of costs and benefits of options for developing specialised intellectual disability health services, at 5.



¹⁰ NSW Agency for Clinical Innovation (2015) Context Report and Toolkit for Health Services for People with Intellectual Disability.

research, training and consultancy support to improve practise in intellectual disability and mental health.

Until 2017, ADHC also funded eleven positions to build expert capacity in intellectual disability and mental health.

If funding is not renewed:

- progress in intellectual disability and mental health will stall; and
- Local Health Districts will not be able to build their capacity in intellectual disability and mental health.

Recommendation 3

NSW Health fund the Chair in Intellectual Disability and Mental Health and 11 new traineeships in intellectual disability and mental health.

Uncertainty over responsibility and funding of eating and drinking management plans for people with dysphagia

People with dysphagia require a mealtime plan to ensure they can eat and drink safely. Participants are not having this support funded in their NDIS plans. The NDIS argues that the mealtime plan aims to prevent a health condition (choking from dysphagia) and is therefore the responsibility of the NSW Health. An interim plan is required until operational practice is established.

Unless responsibility is clearly articulated and accepted, people with dysphagia will die preventable deaths from choking.

Recommendation 4

The NDIA should accept responsibility for the development of a mealtime plan for participants with dysphagia. In the interim:

- NSW Health accept responsibility and fund dysphagia assessments and the development of mealtime plans; and
- NDIA provide reasonable and necessary support to implement the mealtime plan, including training of a person's support workers and informal supporters.

People ineligible for the NDIS will lose their disability support

ADHC funds Community Care Support Program (CCSP) administered by the Department of Health. CCSP provides people with lower level of disability with assistance including personal care, domestic assistance and case management. Approximately 1/3 of people supported by CCSP are projected to be ineligible for the NDIS.



People will face challenges in independent living, leading to an increased likelihood of hospitalisations (for physical and mental health concerns) and increased social isolation.

Recommendation 5

NSW Health continue to provide support for people accessing CCSP services who are ineligible for the NDIS.

The health system lack responsiveness to people with disability

Increasing the health system's responsiveness to people with disability requires coordinated action from NSW Health within and across Local Health Districts.

Recommendation 6

Implementation of a continuous improvement framework as outlined in *The Essentials*, developed by the Agency for Clinical Innovation. This guidance document provides range of self- assessment tools that enable Local Health Districts to map their capabilities and monitor their progress.

Recommendation 7

Develop accessible health information including in alternate formats such as braille and easy read.

Recommendation 8

Provide ongoing training of all health staff in disability awareness and competence, with an emphasis on appropriate communication.



Justice

What is the problem?

People with cognitive impairments are highly represented in the criminal and juvenile justice system.

People with cognitive impairments are 3 to 9 times more likely to be in prison than the general NSW population.^^^

Our members highlight that lack of appropriate support is a crucial factor in the over representation of people with disability in the criminal justice system. Police and legal professionals lack knowledge and expertise in dealing with the challenges faced by people with intellectual disability. 12 This makes it harder for an offender to be

identified as having a disability and to access diversionary options. The system struggles to respond to "complex needs" created by behaviours of concern and being inadequately supported by multiple service systems. Sadly, such offenders are often admitted to psychiatric hospitals or end up in the mainstream system where people with disability are vulnerable to disciplinary action, violence and sexual assault.¹³

ADHC funded programs have attempted to reduce this over representation by providing support to:

- people charged with a crime, by funding the Criminal Justice Support Network (CJSN) to provide support at police stations and in courts;
- offenders before the courts to seek diversionary options; and
- people in custody by funding the Criminal Justice Program (CJP) that offers holistic, specialist and flexible support. We are pleased that this program has been granted a one year extension of funding by the Department of Justice, but its future is uncertain beyond June 2019.

In addition, the CJSN supports victims of crime throughout their court processes including supporting them to make statements to the police.

Notwithstanding the work of the <u>State wide Disability Service</u>, the Justice and Corrections systems need to fund the functions specified in the interface principles. Unless these supports are funded, over representation of people with disability is likely to worsen.

People charged will not be supported through the criminal justice system

Under the interface principles, the Department of Justice has responsibility for the accessibility of legal assistance. Recent research illustrates that if a person with cognitive disability has a support person throughout the criminal justice process, they are more likely to participate and plead in their court matter.¹⁴

Because the Department of Justice has traditionally not provided this support for people with disability and

¹⁴ McSherry B, Baldry E, Arstein-Kerslake A, Gooding P, McCausland R and Arbena K *Unfitness to Plead and Indefinite Detention of Person with Cognitive Disabilities*, Melbourne: Melbourne Social Equity Unit, University of Melbourne. 2017



^{^^^} McCausland et al (2013) People with mental health disorders and cognitive impairment in the criminal justice system; Cost benefit analysis of early support and diversion.

 $^{^{12}}$ See Intellectual Disability Rights Service. Steele, L. (2008) <u>Enabling justice: a report on the problems and solutions in relation to diversion of alleged offenders with intellectual disability from the New South Wales local courts system</u>

¹³ RMIT University and Jesuit Social Services (2016) Enabling Justice Project: Consultation Paper, 25.

people with complex needs, ADHC funds the Intellectual Disability Rights Service to run the Criminal Justice Support Network that:

- supports people with intellectual disability to understand their rights and the legal processes in police interviews and court proceedings.
- provides problem solving and decision support to people with cognitive disability as they are going through the criminal justice system, linking them to disability support wherever necessary.
- supports victims with intellectual disability throughout their court processes including assisting them to make statements to the police.

A small number of staff coordinates 130 volunteers who in 2016-17, supported 600 people.

Without the Criminal Justice Support Network:

- more people with disability will be imprisoned (without rehabilitation);
- Government will face an increase of costs related due to increased number of adjournments and recidivism, such as legal fees, court and custodial costs; and
- fewer people with cognitive disability will have access to diversionary options.

Recommendation 9

The Department of Justice fund a service similar to the Criminal Justice Support Network beyond 2019 with additional funding to ensure coverage to support people with disability across NSW.

People with cognitive disability are not supported to secure diversionary orders

Under the interface principles, the Department of Justice is responsible for the cognitive and psychiatric assessments used to determine eligibility for court sentencing or diversion.

Magistrates have a wide discretion when sentencing a person who is cognitively impaired or has a mental illness, which includes the ability to discharge the offender with appropriate support, after considering evidence in a support plan. Traditionally, ADHC staff conducted assessments and case management where necessary to develop support plans appropriate to people with cognitive disability, facilitating their access to diversionary options.

These roles cannot be funded by the NDIS.

We acknowledge that the Department of Justice is piloting the Cognitive Impairment Diversion Program in Penrith and Gosford Local Courts, enabling offenders with cognitive disability to access assessment and case management.

However, our members are concerned that some elements of this program have a punitive focus (for example, monitoring by Community Corrections) rather than focusing on assisting a person with cognitive impairment to comply with the order.

In addition, there is no support available to offenders in the rest of NSW, and the pilot only runs until October 2019.



As such, with ADHC's closure people with cognitive disability will be more likely to be sentenced and possibly imprisoned due to lack of evidence available to support a diversionary order.

Recommendation 10

The Department of Justice expand a remodelled Cognitive Impairment Diversion Program which takes a holistic approach to supporting the offender, including:

- the assessment of the person's cognitive disability and its impact on the person's life; and,
- short term intensive case management to develop a support plan with the person and actively link the person to NDIS and/or mainstream services.

Lack of holistic wrap around support for offenders with intellectual disability

The ADHC funded Criminal Justice Program (CJP) provided specialist disability services (including accommodation in some cases) to people with intellectual disability and complex needs as they exited prison after committing serious offences. Delivered by non-government organisations, CJP took a holistic approach, beginning to work with the person while they were imprisoned to anticipate their support needs post release. Supports, including case management, were tailored to a person's individual needs.¹⁵

The NDIS interface principles disperse responsibilities that are currently well coordinated in this holistic program. The program was developed in the recognition that for many people with complex needs, it is not possible to differentiate their disability support needs from those arising from criminal behaviour.

With lower levels of fragmented support, people with cognitive disability who would have accessed the CJP will:

"Regarding the justice system ... it is very unclear what it will look like for a person leaving the prison path. They will be losing the ADHC resource. Who will link them in?"

- NCOSS consultation, Kiama, August 2017

- spend longer on remand or in prison because they cannot access disability support (including the NDIS);
- be more likely to reoffend, have contact with the criminal justice system or be admitted to psychiatric hospitals. ¹⁶

Cost benefit studies in relation to people with complex needs have shown holistic support saves \$1.40 - \$2.40 for every dollar spent on support. Total savings to the Government would range between \$1 million-\$5.8 million.¹⁷

¹⁷ McCausland, R, Baldry, E. & PwC 2013 <u>People with mental health disorders and cognitive impairment in the criminal justice system Cost-benefit analysis of early support and diversion</u> Report for AHRC, pp1-12



¹⁵ ADHC Community Justice Program Service Model Description

¹⁶ Community Restorative Centre (2017) <u>Access to the NDIS for people with cognitive disability and complex needs who are in contact with the criminal justice system: Key challenges</u>, at 8.

Recommendation 11

The NSW Government (Department of Family and Community Services or Department of Premier and Cabinet) lead the development of specialist wrap around services for offenders with cognitive disability. These services should have expertise to provide appropriate pre-release planning, intensive disability support and post-release support for people with cognitive disability.

Recommendation 12

Currently funded CJP providers to be given a lead role in supporting the development of growth required.

Other critical steps to improve the responsiveness of the justice system

The justice system needs to take a multi-agency approach to respond to the additional needs of people with disability. Our members emphasise that this involves:

- services taking a flexible and collaborative approach from first contact, strengthening their capacity to
 identify and accommodate young people with disability. This includes recognition via maternal and
 infant health services, early childhood and school education, out of home care and community health
 services;¹⁸
- offenders on remand being screened for cognitive disability, and to facilitate access to diversion programs;¹⁹
- the Police Force building its responsiveness to people with cognitive disability, including by establishing a network of Disability Liaison Officers, including a "specialist" at each police station who can offer advice and support to other officers in relation to responding appropriately to offenders with intellectual disability;²⁰ and
- the justice system providing continuous training to police, lawyers, court support workers and judicial
 officers in recognising, understanding and responding to cognitive disability and complex needs. ²¹

²¹ Baldry, E. et al. (2015) <u>A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system.</u>, at 165.



¹⁸ Baldry, E. et al. (2015) <u>A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system.</u>, at 162.

¹⁹ Baldry, E. et al. (2015) <u>A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system.</u>, at 166.

²⁰ See Intellectual Disability Rights Service. Steele, L. (2008) <u>Enabling justice: a report on the problems and solutions in relation to diversion of alleged offenders with intellectual disability from the New South Wales local courts system</u>, at 6

People with complex needs

What is the problem?

People who are perceived to have "complex needs" often interact with multiple service systems. As demonstrated in the Justice section, their needs are inadequately served as each need is dealt with in isolation. A holistic approach is most appropriate.

The Government has recognised the effectiveness of a holistic response by trialling the Integrated Service Response, but staff are still developing detailed knowledge required to assist people with complex needs.

Lack of holistic wrap-around support for people with complex needs

Funded by ADHC, Housing NSW and Justice Health, the Integrated Services Project for Clients with Challenging Behaviour (ISP) provided individualised, flexible and holistic support for people with complex needs and challenging behaviour over an 18-month period (which could be extended). Modes of support were tailored to an individual's needs, and could include accommodation and case management. Supports are aimed to build a person's capacity and independence, as well as the capacity of mainstream services to support the person. All agencies involved with the person implemented their plans collaboratively.²²

The NDIS distinction between disability and non-disability support needs disadvantages offenders with complex needs who find themselves excluded from mainstream services because of both their disability and complex needs.²³ They are often also included from disability service.

Although the Government is implementing the Integrated Services Response (ISR) for people with complex needs, this does not replicate the intensive holistic support provided by the ISP. Our members are concerned that the 3 month period in which ISR works with a client is insufficient to account for their complex behaviour. While the ISR focus on building systems capacity is important, the individual will no longer benefit from wrap around holistic support.

The impact of this is that people with complex needs will experience poor life outcomes, and there will be significant additional costs to other areas of Government particularly in terms of increased stays in hospital and prison.²⁴

Recommendation 13

The Department of Justice expand the Integrated Services Response to provide holistic support, and ensure staff are equipped with the knowledge skills and expertise required to provide this support.

²⁴ McDermott, S., Bruce, J., Fisher, K.R., and Gleeson, R. (2010), '<u>Evaluation of the Integrated Services Project for clients with challenging behaviour: Final Report'</u>, SPRC Report 5/10, prepared for Ageing, Disability and Home Care, Department of Human Services, NSW, Social Policy Research Centre, Sydney.



²² McDermott, S., Bruce, J., Fisher, K.R., and Gleeson, R. (2010), '<u>Evaluation of the Integrated Services Project for clients with challenging behaviour: Final Report'</u>, SPRC Report 5/10, prepared for Ageing, Disability and Home Care, Department of Human Services, NSW, Social Policy Research Centre, Sydney.

²³ Community Restorative Centre (2017) <u>Access to the NDIS for people with cognitive disability and complex needs who are in contact with the criminal justice system: Key challenges</u>, at 4

Intensive Family Support

What is the problem?

Families can struggle to provide additional support to a child with needs arising from his or her disability. This is especially true if the family is experiencing poverty, insecure housing or domestic violence. Intensive support can assist them to build capacity to care for their child.

Parents with disability often need additional support to fulfil their parenting roles. This additional support is sourced from intensive family support programs in which disability is considered a risk factor for children.

Vulnerable families of children with disability lack holistic support

Until June 2017, ADHC funded:

- Intensive Family Support Options (IFSO) a voluntary program for families under high levels of stress where children were at risk of entering out of home care. Intensive support was provided for 12 weeks, followed by 40 weeks of wrap-around support tailored to the family's individual needs,²⁵ including assistance with bills, clothing and furniture; and
- Extended Family Support (EFS) supplementary funding for families with a child with disability aged 0-18 who was at risk of an out of home care placement. The funding aimed to support families so the child with disability could remain at home.²⁶

These services responded to families facing multiple challenges. For example, as well as the child's disability, a family could be dealing with homelessness, domestic violence and/or drugs and alcohol issues.

These programs will not be funded under the NDIS, which concentrates on the needs of the individual participant (in this case the child). When a family faces multiple and interwoven challenges however, it can be hard to separate a child's disability from a family's non-disability needs.

Our members tell us that the cessation of Intensive Family Support Options and Extended Family Support have led to an increase in the number of children with disability in out of home care, either through family relinquishment or forced removal. Unless holistic support is restored, this situation is likely to worsen.

This gap will have a particularly significant impact on Aboriginal families. They often live in rural, regional and remote areas where intensive services are not readily available.

Recommendation 14

The Department of Family and Community Services fund intensive family support programs for children with disability.

We also endorse ECIA's recommendations in relation to children and their families experiencing vulnerability:

²⁶ Department of Family and Community Services <u>Service Model: 2.07.03 Extended Family Support & Flexible Placements</u>



²⁵ Department of Family and Community Services (2011) Intensive Family Support: Service Provision Guidelines. at 6

7.1 Establishment of *regional case conferencing initiatives for complex families* with a child age 0-6 with an NDIS plan, which require supports from multiple NSW Government services. The regional case conferencing initiative is to be based on sound family centred practice and would feature:

- Guidance on establishing roles and responsibilities of different agencies in that specific set of circumstances; Process, policies and documentation that support development of a plan for working together which identifies responsibilities, timelines and outcomes;
- Participants to consider how to pay for collaborative work (under the NDIS, ECI providers need permission from the child's parent to bill for collaborative time from the child's NDIS plan); and
- Develop How To Guides, case studies and Frequently Asked Questions.

7.2 Expanding Family Support services such as MyTime and Brighter Futures to meet the needs of families experiencing vulnerability through an outreach based and collaborative approach.²⁷

Parents who have a disability fear their child will be removed if they seek support for parenting

Our members tell us that parents, and especially mothers, with disability are fearful of seeking the support they need to parent effectively because the intensive support comes from a child protection focus and their disability is considered a factor that places their child at risk.

Parents with disability risk feeling disempowered to seek the support they need, and this lack of support can put children at risk.

Recommendation 15

The Department of Family and Community Services provide support to parents with disability who are not NDIS participants to undertake their parenting roles.

Children with disability in voluntary out of home care may lose the option of foster care

FACS has supported foster families who provide out of home care to children with disability through:

- allowing foster carers to claim payments (the alternative family allowance) if the child lived with them
 after age 18, recognising that the child's disability needs can be such that the parent is unable to work,
 or forced to work a limited number of hours; and
- respite support, facilitating the child to periodically stay at alternative accommodation.

These supports are not provided under the NDIS, leaving foster carers stretched and fearing they will not be able to support the child long term. The NDIA position that caring for the child falls within the domain of parental responsibility does not recognise that there are significant disability needs as a child.



²⁷ Early Children Intervention Australia (2018) Gaps in Services Age 0-6 with Developmental Delay and Disability.

Consequently, there will be a reduction in the number of foster carers for children with disability, forcing those in out of home care to live in inappropriate group accommodation. This will also lead to a lack of stability for vulnerable young people with disability.

Recommendation 16

The Department of Family and Community Services takes responsibility for compensating foster carers for the additional support required when a child has a disability. In addition, the NDIS Plan for a child with disability in foster care should include support for short breaks in an alternate location.



Transport

What is the problem?

Many people with disability, particularly in regional areas, use community transport to enable them to participate in the community and attend to their health needs. ADHC provided one source of funding for community transport; its cessation will leave resources stretched and people with disability potentially isolated.

We commend Transport for NSW for maintaining the NSW Taxi Transport Subsidy Scheme, regardless of a person's eligibility for the NDIS. This approach to assisting people who are transport disadvantaged should be also applied to community transport.

Less funding for community transport for people with disability

Community transport provides personalised transport options to people with disability who are unable to use public transport (as well as older people and people who are transport disadvantaged). Community transport providers were traditionally block funded from a mixture of three sources:

Program	Funder	Focus
Commonwealth Home Support Program	Commonwealth Department of Health	People over 65
Community Care Support Program	ADHC and administered by Transport for NSW	People with disability under 65
Transport disadvantage	Transport for NSW	People in rural and regional areas

Block funding allowed consumers to be charged a contribution for their trips with government funding covering the full cost of transport. Transition to the NDIS has had a significant impact:

- The Community Care Support Program (CCSP) funding ceased in December 2017, with funding transferred to the NDIA even though one third of people eligible for CCSP are not expected to be eligible for the NDIS.
- Trips began to be funded on a cost recovery basis. Small user contributions became unsustainable and the price of travel became unaffordable for most users.

As a result, people are missing out on important health appointments and other commitments, and remaining socially isolated.

"People have to spend whole day in town because the round trip [on the accessible bus] starts in the morning and finishes at the end of the day."

– NCOSS consultation, Orange, August 2017

There is also the risk of increased demand for the transport disadvantage portion of funding and loss of community transport infrastructure as many transport providers go out of business.



We acknowledge the March 2018 announcement of investment in community transport, but advocate for funding the previous election commitments below.

Recommendation 17

Transport NSW significantly increase transport services and supports available to people with disability who are unable to use public transport and people experiencing transport disadvantage. Guidelines for the expanded funding pool should:

- retain previous CCSP eligibility criteria to ensure continuity of access; and
- broaden eligibility criterion for community transport to clearly include transport disadvantage.

A man with disability living on the mid-north coast previously used community transport to participate in the community and to attend appointments. Before the changes to community transport funding, he paid \$70 for a trip with community transport to the main town centre, about two and a half hours his home. Under the changes, the trip is now charged at \$300 limiting his participation in the community and leaving him depressed at home. — Source: NSW Council for Intellectual Disability

A community transport customer compared the number of trips she can currently take compared to those prior to the NDIS and notes: "In simple financial terms, I am three time worse off. My transport allowance only allows me one trip per week by taxi to a doctor, dentist, specialists, meetings or for shopping in the town nearby." – Source: Community Transport Organisation



Housing

What is the problem?

Compared to people without disability, people with disability face additional barriers to securing a safe and affordable home. People with disability are often of low income, exacerbating challenges in affordability. People with mobility impairments are further limited in their housing choices by a significant lack of accessible or adaptable housing stock across the private, rental and social housing markets.

The housing needs of people with disability will largely be unmet by the NDIS; only 6% of participants are eligible

for Supported Disability Accommodation (SDA). Nationally, this leaves between 35,000 and 55,000 NDIS participants fully reliant on State Governments for affordable, accessible accommodation.²⁸ One-third of these are expected to live in NSW.

With the closure of ADHC, it is critical that both the Housing and Planning Departments take action to overcome the barriers faced by people with disability in accessing various housing options.

Our members emphasise that all housing options need to be truly 'accessible' which includes located close to public transport, shops and other facilities.

People with disability do not access social housing in proportion to their income disadvantage.

79% of people with disability have low or very low incomes, but only 13.5% are public renters. Meanwhile, 45% of people with disability own their homes compared to 70% of the general population.*

Social housing

Housing allocations do not target people with disability

Demand for social housing far exceeds supply, forcing people with disability to compete with other vulnerable groups. A targeted stream of social housing would address this challenge, ²⁹ better demonstrating the demand for appropriately designed and located housing that decreases a person's disability support costs.

While the Social and Affordable Housing Fund (SAHF) is most welcome, there is no allocation within the SAHF focused on accessible housing for people with disability, meaning people with disability have not had equitable access to the increased supply.

People with disability therefore risk staying on waiting lists indefinitely, without being prioritised for social housing.

²⁹ Wiesel et al (2015) Moving to my home: housing aspirations, transitions and outcomes of people with disability, at 34.



^{*(}Wiesel et al (2015) Moving to my home: housing aspirations, transitions and outcomes of people with disability, at 34.)

 $^{^{28}\} Disability\ Housing\ Futures\ \textit{Modeling the disability housing gap\ and its\ impact\ on\ lifetime\ support\ costs}, University\ of\ Melbourne,\ 2017.$

Recommendation 18

The Department of Family and Community Services or Housing NSW introduce:

- allocations of social housing specifically targeted at people with disability;
- a NSW Affordable Disability Housing Strategy with a focus on accessibility; and
- equitable access to capacity to borrow for housing programs targeting housing for people with disability, as recommended by the Affordable Housing Working Group (the Working Group) of the Council on Federal Financial Relations.

Housing allocations do not take sufficient account of disability requirements

Our members tell us that Housing NSW does not account for the disability-specific requirements their clients face when seeking social housing. For example:

- they are ineligible for priority housing if they have been living with family or living in shared supported accommodation;
- they are offered housing that is unsuitable for their access needs, despite specifying these on their application. This disadvantage is exacerbated by the requirement to inspect a property within 24 hours;
- long wait times for repairs (including to heating and cooling) make life difficult for people with disability who are less able to adjust their lifestyle; and
- if they need a carer, they face challenges securing an additional bedroom at an affordable rent.

People are therefore being forced to remain in inappropriate housing, often facing a deterioration of their disability.

Recommendation 19

The Department of Family and Community Services or Housing NSW makes changes to current housing processes so that:

- people with disability living in unsustainable or restrictive situations are included in priority allocations;
- people who need a carer have access to an additional bedroom at an affordable rent as proposed in the National Disability Strategy;
- applicants are not disadvantaged by declining an offer;
- transparent accessible information is available about available lettings and allocations criteria;
- support is available during bidding process; and
- repairs required by tenants with disability are prioritised.



Private rental market

The private rental market does not provide security of tenure

People with disability are often vulnerable tenants, their choice limited by their low income. They are also more likely to have limited access to properties on the private rental market.

An Anglicare Australia survey found that there were no affordable properties in Sydney for people on the Disability Support Pension (DSP).³⁰

Disability can often limit mobility, increasing the importance of secure housing. Our members tell us that unfortunately landlords often discriminate against tenants (or potential tenants) with disability who experience evictions pursuant to no grounds eviction under the *Residential Tenancies Act 2010* (NSW).³¹ Termination without cause has a harsher impact on tenants with disability.

NCOSS and its members support the *Make Renting Fair Campaign* by focusing on the removal of no-grounds eviction.

Recommendation 20

The Minister for Housing amend the *Residential Tenancies Act 2010* (NSW) to remove the ability to evict other than on specified grounds.

Home ownership

NSW has no proactive measures to increase home ownership by people with disability

Most people with disability who become home owners do so through support from family, use of inheritance or compensation and shared equity schemes.

Western Australia, South Australia and Tasmania have shared equity schemes that have increased home ownership by people with disability.³² The shared equity scheme enables the home to be owned jointly by the person with disability and a shared equity partner such as a financial institution, a government department, or a not-for-profit housing organisation.

Currently, home ownership by people with disability in NSW is very low.

Recommendation 21

Housing NSW develops a shared equity scheme targeted at people with disability.



³⁰ Anglicare Australia (2017) *Rental Affordability Snapshot*, at 4.

³¹ Sections 84, 86, 94 of the Residential Tenancies Act 2010 (NSW).

³² Wiesel, I et al (2017) Shared home ownership by people with disability, at 22-28.

Accessible housing

Supply of accessible housing does not meet demand

It is difficult to ascertain what percentage of properties is accessible or adaptable, especially as developers are reluctant to pay for Livable Housing Australia certification. ³³ There is no way to know whether the situation is improving.

Recommendation 22

Housing NSW ensures that all FACS/Housing NSW properties are built to Silver Liveable Housing Australia standard.

Recommendation 23

Housing NSW continues to support the national move to include minimum accessibility standards in the National Construction Code with the commitment to consult disabled persons and advocacy organisations in the Regulatory Impact Assessment process due to start in mid-2018.

People with disability experience challenges in locating suitable properties

Our members tell us that prospective tenants find it hard to locate accessible properties, and face challenges in negotiating with landlords who allow modifications (even though they are required to do so under the *Disability Discrimination Act 1992* (Cth)).

This means people with disability are unable to locate properties with the adaptable and accessible features they require, while adaptable and accessible properties are rented to people who do not need these features.

Recommendation 24

Housing NSW supports the development of central repository of information about adaptable and accessible housing.

Further, under the NDIS interface principles, the Government is responsible for modifications to social housing stock, but people with disability experience serious challenges in having home modifications completed in a timely manner.

This means that people with disability often are forced to remain in hospital or move into a nursing home over home modification challenges. They may also be forced to live in housing that does not meet their needs, including the ability to shower.

Modification must occur in a timely manner to avoid this issue.

³³ The minimum universal standard of accessibility should be the Livable Housing Australia silver standard of accessible design, and new developments should include targets for the incorporation of accessibility higher standards.



Planning regulations do not promote accessible, affordable housing

Currently, developers are not incentivised to ensure that new developments include a certain percentage of affordable housing for sale or lease. Consequently there is an inadequate supply of accessible, affordable housing.

State and local governments could place requirements on developers to achieve significant increases in affordable housing built to Silver Liveable Housing Australia standard.

Examples of requirements used by other States and Territories include inclusionary zoning policies, such as the South Australian Housing Strategy commitment to ensuring that at least 15% of all new housing (government and private land developments) in significant developments is affordable to low and moderate income households.

The Affordable Housing Working Group³⁴ outlined a range of strategies that could lead to a significant growth in affordable housing.

Recommendation 25

Planning NSW implement the recommendations of the Affordable Housing Working Group to enforce or encourage the development of affordable housing, including change of use controls on land or buildings, density bonuses, inclusionary zoning and developer levies that fund the construction of affordable housing.

³⁴ Affordable Housing Working Group (the Working Group) of the Council on Federal Financial Relations (2016) Innovative financing models to improve the supply of affordable housing.



Overcoming the challenges: The role of advocacy and information

Independent disability advocacy and information organisations have played a critical role across Government:

- Assisting individuals with disability to solve problems and negotiate barriers and systems.
- Identifying systemic barriers and working with Governments to build inclusive solutions.
- Representing the voice of people with disability in policy development, drawing on a wide range of experiences.

Advocacy provides an 'early warning' system, identifying issues before they escalate at greater costs. An upfront investment in advocacy can prevent future obstacles arising. A recent cost-benefit analysis showed investment in disability advocacy results in substantial cost savings to Government while creating benefits for people with disability across their lifespan.³⁵

The NDIS has not decreased the need for advocacy. On the contrary, our members report an increase in demand for advocacy services since the introduction of the NDIS; as people with disability lose

"It's all very well to say choice and control, but unless you have someone to go to [an advocacy service] this isn't going to happen to the extent it needs to." - NCOSS consultation, Coffs Harbour July 2017

services and struggle to navigate a complex system without assistance. People 'on the fringe' traditionally assisted by outreach services are particularly vulnerable. Advocacy and information play a critical role in enabling people with disability to realise the choice and control on which the NDIS is built.

Drawing on case studies from our members, this section explores the role and contribution of advocacy and information organisations across each portfolio of government. As highlighted in this report, the role of advocacy will be even more crucial with the closure of ADHC.

The recent commitment to two years of additional funding for disability advocacy and information representation organisations in NSW is very welcome. However, ongoing funding is needed to ensure people with disability can access assistance to navigate mainstream systems, and that Government can benefit from expertise of advocacy partners as it fulfils its responsibility under the *Inclusion Act 2013*. The vital supports provided by advocacy information and representation organisations to people with disability and Government were never intended to be covered by the NDIS.



 $^{^{35}\,}Daly, A\,and\,Barett, G\,(2017)\, "A\,Cost\,Benefit\,Analysis\,of\,Australian\,Independent\,Disability\,Advocacy\,Agencies"$

Health

Tina has an intellectual disability. Although she is in severe pain, she is reluctant to go to the doctor; she has lived in institutions where medical professionals treated her poorly, and she is isolated and fearful.

A trusted advocate accompanies Tina to the doctor. The advocate explains Tina's fear, and encourages the doctor to communicate appropriately with Tina, explaining each stage of the process. Tina, the advocate and the doctor decide it is most appropriate for Tina to be examined under sedation.

Sadly, the examination reveals that Tina has advanced cancer, from which she dies shortly after. The cancer is likely to have been preventable if Tina had sought help earlier.

Systemic and representative advocacy have achieved a number of outcomes to prevent further premature deaths including the development of:

- medical fact sheets in Easy Read;
- training for doctors to communicate effectively with people with disability;
- the Comprehensive Health Assessment tool to assist GPs to effectively screen patients with cognitive impairment;
- a Medicare number to acknowledge the additional time required to provide medical services to people with disability;.
- the NSW Health Service Framework to Improve the Health Care of People with Intellectual Disability;
- more informed decisions through the use of NSW Health's Intellectual Disability Advisory Committee,
 NGO Advisory Committee and the Intellectual Disability Network of the Agency for Clinical Innovation;
- a requirement for all GP surgeries to have at least one height adjustable bed, to enable people with mobility impairments to be fully examined.

Education

A parent contacted an advocacy organisation after her son was continually suspended because of behaviour related to his disability. The advocate explained the Department of Education's policy and suggested the parent meet with the principal to request her son's teacher be supported to adjust the curriculum and teaching practice to support more effective student engagement.

When the parent was nervous to proceed, the advocate held a teleconference with the parent and their supporter to assist them to prepare for a meeting with the principal. The meeting with the principal went well. He was amenable to the parent's suggestions and agreed that the parent would be part of the initial meeting to brief the Behaviour Support teacher.

Systemic and representative advocacy have achieved a number of outcomes for students with disability:

- stronger Disability Discrimination Standards for Education;
- more inclusive education policy and practice to enable students with disability to be included in their local school;
- improved educational opportunities for children and young people with disability.; and



more effective legislative oversight including clearer understanding of continued barriers. This led to the
recent Legislative Council Inquiry into <u>Students with a disability or special needs in New South Wales</u>
<u>schools.</u>

Advocacy is still needed to implement the report's recommendations and ensure an inclusive school system.

Housing

Housing NSW contacted an advocacy agency about a client, Kwang. She was a social housing tenant with disability and limited English, and the private owner of the property she leased from Housing NSW wanted to move back in.

The advocate explained to Kwang why she had to move and what the process would be. They discussed Kwang's needs and preferences for a new home, using an interpreter so Kwang could be involved. When Kwang was offered a property with numerous steps, (which she indicated on her application she could not navigate), the advocate ensured that this property did not count as one of the two suitable offers by Housing NSW.

The advocate supported Kwang throughout the offer, acceptance, lease signing and organising for Housing NSW to pay for the cost of the move.

Systemic advocacy and representation have achieved:

- Legislative protection for people with disability living in licensed boarding houses. In 2012, new standards were introduced into the *Boarding House Act* to promote the rights of vulnerable residents. The advocacy for the improved standards grew out of the Boarding House Advocacy Project that provided information and advocacy supports to people with disability in licensed boarding houses. The industry is still implementing these standards: Continued advocacy is critical to ensure accountability.
- Improved inclusivity of domestic violence services. Working with Domestic Violence NSW, People with Disability Australia have developed a guide for domestic violence services, highlighting the multidimensional aspects of accessibility. Beyond physical accessibility, the guide asks services to evaluate whether their staff are trained to communicate appropriately to people with disability, and consider whether their processes are inclusive.

Justice

Corrective services contacted an advocacy organisation about Bill, a man with intellectual disability who was in remand for several months. He had breached an AVO a neighbour had taken out against him, but did not understand the terms of the AVO. Neither his accommodation service nor his lawyer had offered any solution to satisfy the court to release him on bail.

The advocate managed to find Bill alternative short-term accommodation. A solicitor from the disability legal advocacy organisation got the matter back before the court and successfully argued for Bill to be released and his matter to be dismissed on the condition that his accommodation changed. The advocate remained involved to ensure that Bill ultimately had permanent accommodation away from the neighbour.

³⁷ People With Disability Australia, and Domestic Violence NSW (2015). Women with disability and domestic and family violence: A guide for policy and procedure NSW: People With Disability Australia.



³⁶ Women with disability are highly represented as victims of domestic violence, but few domestic violence shelters are accessible

Systemic advocacy and representation have achieved:

- recognition of people with disability, particularly those with cognitive impairments as a vulnerable group within the justice system; and
- support for people with cognitive impairment in contact with the justice system as victims and defendants through the CJSN.

Transport and infrastructure

Systemic advocacy and representation have achieved:

- Improved accessibility of transport and public buildings. Advocacy organisations have been instrumental in ensuring accountability for upgrades through public transport to ensure accessibility. Systemic advocacy has also been needed to ensure the Government follows through with commitments in their public landmarks such as the Harbour Bridge.
- Best practice signage. Advocacy organisations have worked with Transport for NSW and the City of Sydney on developing accessible wayfinding signage, including design and piloting of the Tactile Braille Street Signage attached to Smart Poles throughout the Sydney CBD.
- Improved systems and processes in Transport for NSW for people with disability. Our members commend the approach of Transport for NSW, which brings together representatives of a range of disability organisations in the Accessible Transport Advisory Committee (ATAC). Organisations comment on infrastructure development proposals from the perspective of people with disability, identifying current, potential and emerging accessibility barriers. Feedback from ATAC members led to Opal Cards being available at Service NSW centres, as well as online and via phone.

Care and protection

Kate has a learning disability and had recently given birth. Family and Community Services (FACS) were expected at the hospital to undertake a safety assessment. Kate who had grown up in out of home care was very distressed to find that there was a risk of her baby being removed. The advocate talked with Kate about possible options that might help to satisfy FACS so that the baby could safely remain with her. When Kate refused to talk with the FACS workers the advocate became the messenger between Kate and FACS workers. An agreement was reached and Kate was able to leave hospital with her baby. The advocate has remained in regular contact with Kate and actively assists her when there are crises on the horizon.



Conclusion

This report demonstrates that the closure of ADHC presents challenges to Departments across the NSW Government, posing risks to people with disability who will no longer have access to specialist services to meet their needs. A whole of Government response is essential if these challenges are to be addressed.

Implementation of the recommendations in this report requires overarching leadership and coordinated action across Government. We recommend that the leadership and oversight roles be undertaken by a Minister for Disability working together with the Department of Premier and Cabinet.

Transition to the NDIS should increase the choice and control of all people with disability in NSW. Mainstream services need to build their capacity to respond effectively.



Appendix: Challenges in the transition to the NDIS

Challenge	Impact	Recommendation for NDIA		
	Health			
Artificial divide between speech and swallowing assessments for people with Motor Neurone Disease.	Without good assessment of swallowing issues including saliva management a person's speech is be more greatly affected.	Fund comprehensive speech pathology assessment of both speech and swallowing.		
NDIA funds speech but not swallowing assessments. Issues interrelated and need to be assessed together.	Greater risk of aspiration and weight loss. Social isolation .			
Uncertainty over responsibility and funding of eating and drinking management plans for people with dysphagia.	Unless responsibility is clearly articulated and accepted, people with dysphagia will die preventable deaths from choking.	Support the implementation of mealtime management plans including training for support workers and informal supporters.		
Inconsistency in the interpretation of the applied principles related to whether some nursing services (e.g. catheter change) OT and physio are disability or health related expenses.	NDIS participants are prevented from receiving these supports from Community Health Centres but are not always able to receive them as part of reasonable and necessary support.	Provide clear operational guidelines to ensure consistency of approach. Develop a protocol with state health systems for provision of this support where a person is not eligible for the support under the NDIS.		
People with high support needs/ intellectual disability are not supported for in-patient and outpatient hospital services	People with disability inadequately and inappropriately supported in hospital, exacerbating challenging behaviour	Reasonable and necessary support must provide adequate level of core support so that individuals can attend medical appointments/hospital when		
NDIS plans and Supported Independent Living (SIL) does not account for the fact that some people need to be assisted by a disability support worker, in some cases more than one support worker while in hospital or having medical procedures.	People with disability lack access to proper care and treatment, exacerbating poor health outcomes.	needed, with assistance provided by familiar support workers.		

Challenge	Impact	Recommendation for NDIA
Participants are receiving inadequate support for assistive technology (AT) in their plans. Specific funding allocated for AT in the participant plan does not provide adequate coverage for maintenance when problems arise. Spinal Cord Injury Australia indicates that their members have average of \$750 per plan for maintenance. Where maintenance costs are above this, the participant must seek a plan review to get more funding.	With inadequate AT support, participants are less independent and may need more core support. Inadequate funding for repairs means that participants do not have equipment while waiting for a plan review. Meanwhile the participant may not have crucial equipment like a functioning wheelchair or height adjustable bed.	Implement planned changes to participant planning processes around AT. Ensure funding for repairs is available as required.
NDIS does not deal appropriately with specific needs of people with psychosocial disability, including using language inconsistent with the recovery model.	People with psychosocial disability cannot access appropriate assistance; impairment may worsen.	Proposed changes in the Tailored Pathway for participants with psychosocial disability reflect feedback from organisations representative of people with psychosocial disability.
	Justice	
Lack of holistic wrap around support for offenders with intellectual disability including post release. The Criminal Justice Program began to work with offenders in prison, anticipating their needs post release. The NDIS distinction between disability and non-disability support needs disadvantages offenders with complex needs who are often excluded from both disability and mainstream settings. ³⁸	 With lower levels of fragmented support, people with cognitive disability who would have accessed the CJP are: spending longer on remand or in prison because they cannot access disability support (including the NDIS); and more likely to reoffend, have contact with the criminal justice system or be admitted to psychiatric hospitals.³⁹ 	Continue work on the Tailored Participant Pathway identify specialist planner and Support Coordinator positions to undertake planning and plan implementation support for offenders with cognitive impairment. This includes engagement and planning 12 weeks prior to leaving prison.

³⁸ Community Restorative Centre (2017) Access to the NDIS for people with cognitive disability and complex needs who are in contact with the criminal justice system: Key challenges, at 4

³⁹ Community Restorative Centre (2017) <u>Access to the NDIS for people with cognitive disability and complex needs who are in contact with the criminal justice system: Key challenges</u>, at 8.

Challenge	Impact	Recommendation for NDIA
	People do not engage in the community and this increases the likelihood of reoffending.	
	People with complex needs	
NDIS does not deal appropriately with people with complex needs, including providing them inadequate behaviour support.	People offend, end up in jail, are inappropriately placed in general or psychiatric hospitals or live in other circumstances with restrictive practices.	Monitor and evaluate the Tailored Participant Pathway for NDIS participants with complex needs.
	Intensive Family Support	
Parents who have a disability fear their child will be removed if they seek support for parenting. Their disability is considered a risk factor for their child.	Parents do not come forward to seek the support they need. This can in fact put children at risk.	Provide reasonable and necessary support in a participant's plan to enable them to undertake their parenting roles.
	Transport	
Inadequate transport funding in participant's plan.	Participants are using core supports to cover transport needs and are restricted in daily living and/or risk social isolation.	Allocate transport in the participant's plan on a reasonable and necessary basis, as with other supports.
People ineligible for the NDIS lose entitlement to Mobility Allowance. The Social Services Legislation Amendment (Transition Mobility Allowance to the National Disability Insurance Scheme) Bill 2016 will restrict access to the critical transport support to only those eligible for the NDIS.	People with disability ineligible for the NDIS will face many barriers workforce participation, and experience greater social isolation.	Senate should reject Mobility Allowance Bill. Commonwealth Government should continue to fund the Mobility Allowance, recognising it as a participation support rather than a disability support.