Citizens with disability at the heart of the National Disability Strategy:

Submission to the Department of Social Services

October 2020

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EXECUTIVE SUMMARY

Citizens with disability at the heart of the National Disability Strategy

For the National Disability Strategy (the Strategy) to have an impact in enabling people with disability to become active citizens, Commonwealth, State, Territory and Local Governments must demonstrate leadership through the vision and plans they have co-designed with people with disability and the rigour by which they measure and report on outcomes. A Strategy that truly puts citizens with disability at its centre will ensure that commitments and obligations under the National Disability Agreement are reflected in other Commonwealth-State and Territory Agreements to strengthen the visibility of a whole of government responsibility to people with disability.

The success of this Strategy will be measured by the extent to which it closes the gap between people with and without disability in areas of economic security, inclusion, rights protection, education, health and wellbeing. Support for people with disability to co-design the Strategy and monitor its implementation will be pivotal and must be visible in mechanisms that support leaders with disability to flourish in government, in the community and in Disabled Persons Organisations (DPOs). A strengthened national network of DPOs will be integral to building active citizens with disability who lead good lives and can partner with government and the community to facilitate an inclusive Australia.

The Strategy must showcase government actions that facilitate a fair Australia in which all citizens have equitable access to opportunities. The community expects a decision-making body at the highest level, reporting to Parliament annually on progress, with new legislation and major initiatives reviewed in terms of their impact on the closing the gap for people with disability. A renewed Disability Reform Council, the establishment of proactive State Commissions for Disability Equality and requirements on government related to employment and procurement are just some of the features of a Disability Strategy that means to achieve outcomes.

The Independent Advisory Council (Council) is pleased to see a commitment to improved accountability in the next Strategy and will look for rigorous systems to collect, disaggregate, disseminate and report on data to measure progress, the inclusion of commitments of the National Disability Agreement in the relevant Commonwealth-State Agreements, the reestablishment of a National People with Disability Council to partner with the Commonwealth Government in the design and implementation of the Strategy, progress reflected in KPI's of Departmental Heads and the establishment of reference groups in each government department that guide responsive service provision and practices of a model employer of people with disability with reference groups co-chaired by an executive member of the government agency and a senior staff member with a disability.

A strong Strategy that seeks to change outcomes will also include multi-faceted, well-resourced and prolonged strategies to change attitudes and support a community strengthened to welcome people with disability. It will also work with the tertiary education sector to ensure all courses of study include a unit that examines the impact of professional practice on the participation and inclusion of people with disability.

Seamless interfaces

The next National Disability Strategy must provide a seamless bridge across the interfaces between the National Disability Insurance Scheme (NDIS) and mainstream services so that no person with disability is left without critical support as a result of the territorial battles of government. The interface principles anticipated the complexity of navigating multiple service systems but required each system to coordinate support up to the limit of their responsibility. No-one was authorised to coordinate support at the local level across interfaces, a challenge often too great for an individual and their case manager or support coordinator.

Positive examples of cooperation in the first Strategy were characterised by participation of people with disability at all levels of design and implementation, integration of resourced local government activities with measures at other levels of government and linking of localised initiatives to broader system changes. [1]

The new Strategy must build on these positive features to facilitate a collaborative and coordinated approach across interfaces, committing to solve challenges from the perspective of the individual, rather than the system, addressing barriers to support rather than hinder disability in changing practice, building bridges at the systemic and local level and authorising coordinated cross-sector approaches that provide agencies with resources to seed local initiatives that must subsequently be evaluated for emerging practice.

Information, Linkages and Capacity Building

The Information, Linkages and Capacity Building (ILC) services provided the NDIS with a vehicle for building the capacity, confidence and competence of individuals with disability to use mainstream services and actively participate in community. For participants, the ILC services reduce the demand for reasonable and necessary support, maximise access to mainstream, community and informal supports and make supports more effective at helping people achieve their goals.

For non-participants, the ILC provides information and referral to mainstream and community services and supports community and mainstream organisations to be more welcoming. These are strategies that build the confidence and competence of non-participants to lead rewarding lives in the community. They also reduce pressure to enter the Scheme because non-participants can get the support they need in the community that is more responsive as a result of ILC activity.

Whoever commissions ILC services has increased capacity to influence the delivery of supports at a systemic level. Council shares the concerns raised by the disability community and DPOs about ILC being removed from NDIA, due to the risk of disconnection between ILC and NDIA priorities. Council believes that, for the ILC to produce the desired outcomes under the administration of DSS, there should be a strong focus on alignment between the NDIA and DSS.

The NDIA has deeper connections to people with disability and communities, a range of advisory structures to ensure decisions are participant-focused and links to services and

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[1] Davy, L., Fisher, K.R., Wehbe, A., Purcal, C., Robinson, S., Kayess, R., Santos, D. (2019). *Review of implementation of the National Disability Strategy 2010-2020: Final report. (SPRC Report [4/19)*. Sydney: Social Policy Research Centre, UNSW Sydney. http://doi.org/10.26190/5c7494b61edc4

supports of an operational and practical nature, not just at policy level. The NDIA is therefore best placed to know what is required, to target provision and to review the efficacy of local initiatives ensuring they complement but do not substitute for individual and mainstream services.

Disconnection of the ILC from the NDIS can strengthen the divide between NDIS participants and the majority of people with disability who do not meet NDIS access requirements (non-participants) thereby increasing pressure from non-participants to enter the Scheme. In addition, there is a danger that ILC services will develop only for non-participants obviating the benefit that derives from participants and non-participants joining together. This can lead to additional financial pressure placed on the NDIS to provide individual capacity building entirely through reasonable and necessary support, posing a risk to the sustainability of the NDIS. The synergies are optimised by maintaining the relationship between the NDIA and ILC and ensuring maximum alignment of investment and effort to benefit the largest number of people with disability.

A clear link between ILC and the NDIS also ensures the Scheme is seen as a vehicle of support for all Australians with disability, with most people having access to information, referral and support from community organisations and a smaller number becoming participants eligible for individual packages of reasonable and necessary support.

Key actions recommended for the next Strategy include ensuring effective cooperation and alignment between NDIA and DSS around setting priorities for ILC; ensuring transparency of this process, working closely with people with disability and the disability sector and establishing evaluation and reporting mechanisms.

Health

Substantial evidence of health inequalities makes it clear that the Australian health system is failing people with disability. NDIS participants are more likely to report more challenges in accessing health services than the general population, particularly related to access, attitudes and expertise of health professionals. The finding by Bigby[2] that promising practices of supporting people with disability in hospital are 'serendipitous and uneven' and thereby not recognised, shared or taught, and that some people with cognitive impairment remain in hospital long after returning to pre-admission health and functional status, demonstrates the costly impacts for both people with disability and the health system.

Whilst some states and territories have taken positive steps, acknowledgement of failings is a first step to addressing them. Key strategies recommended for the next Strategy include a review of Medicare items to ensure they provide the extra time people with disability need for accurate and respectful diagnosis and treatment, incentivising rather than penalising access to health care; the exploration of health profiles related to disability support needs; consultancy support to improve practice; training for health professionals and requirements on health initiatives, data collection, analysis and research to ensure targeted actions address problems that underlie the inequitable health outcomes of Australians with and without disability.

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[2] Bigby, C., Douglas, J., & Iacono, T. (2018). *Enabling mainstream systems to be more inclusive and responsive to people with disabilities: Hospital encounters of adults with cognitive disabilities*. Report for the National Disability Research and Development Agenda. Melbourne: Living with Disability Research Centre, La Trobe University. P6

Early childhood

Inclusion is now recognised as a fundamental to early childhood intervention with 2 of the 8 principles of best practice emphasising inclusive and participatory practices and engaging the child in natural environments.

Some staff in early childhood education and care settings however are not confident in supporting children with a diverse range of needs and the level of inclusion support and skilled workforce is variable across settings and across jurisdictions. Many settings also struggle to provide equipment that a child with additional needs may require.

Key actions recommended for the next Strategy include all jurisdictions committing to provide coordinated action and additional resources for inclusion support, to build workforce capability and to provide assistive technology and equipment children with additional needs require.

Child protection

The overrepresentation of children with disability in child protection systems leads to disability being considered a risk factor for child safety, placing parents with disability at higher risk of having their children removed, and children with disability at higher risk of being removed from their families. Little attention however is paid to strategies to mitigate that risk and support children and young people to thrive in well supported families.

Many challenges reflect the scant attention paid to disability in the National Framework for Protecting Australia's Children 2009-2020. Universal parenting programs are seldom adjusted to enable participants with cognitive or psychosocial disability to gain core competencies and parents with disability may consequently be notified to child protection agencies without their knowledge, depriving them of the opportunity to secure additional parenting support.

Key actions recommended for the next Strategy include a focus on disability in the renegotiated National Framework for Protecting Australia's Children, requirements that child protection risk assessment tools guide workers to view parents in the context of supports, that NDIS participants notified to child protection agencies are referred back into the NDIS for an urgent plan review for navigational and practical support and that mainstream parenting programs are required to make reasonable adjustments to enable parents who have a disability to gain the core competencies required.

Families and carers

Actuarial data indicates that whilst health and wellbeing of participants has improved under the NDIS, health and wellbeing of families and carers has deteriorated with at least one third of families and carers identifying as not well supported and more than 85% of those who report being unable to work as much as they want citing the situation of their family member with disability as a barrier to greater workforce participation.[3]

Carer resources have been significantly depleted with the introduction of NDIS. The Australian Government new model of carer support services does not replace, let alone increase the

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[3] June 2020 NDIS Quarterly Report p115

level of resources devoted to carer support prior to the NDIS with some State and Territory Governments providing no support in the post-NDIS environment.

Key actions recommended for the next Strategy include the development and resourcing of a new National Carer Strategy that increase resources to family and carer support to at least pre-NDIS days and provides a clear seamless pathway to support for carers in their own right. A commitment is also required of State and Territory Governments to increase resources to family and carer support programs.

Education

The Australian Civil Society Report to the United Nations on the Rights of Peoples with Disabilities (the Shadow Report)[4] documents the challenges experienced by students with disability in Australian schools with evidence of routine discrimination, lack of supports, inadequately trained teachers, lack of expertise and an entrenched systemic culture of low expectations. The lack of national data on suspension, restraint and seclusion of students with disability in the context of increases in segregation over the past decade demonstrates the need for significant action on education in the National Disability Strategy.

The Coalition for Inclusive Education identifies the levers for change required in legislation and policy, more effective monitoring and accountability, parent education and support, teacher education, transformation of school cultures for inclusion and giving students' agency and voice. The fact that a 2019 survey[5] found that 15.1% of students used NDIS funding to assist them to access and participate in education[6] also indicates that nationally, education systems are not providing adequate support for inclusion and this was especially evident in the pandemic.

Key actions recommended for the next Strategy include a National Action Plan for Inclusive Education that includes a legislative and policy framework that fully complies with Article 24 of the Convention on the Rights of People with Disability (CRPD), and a national plan for support for children and young people being schooled at home in the pandemic including clarification and resourcing of the roles and responsibilities of the NDIS and mainstream education.

Employment

The poor employment rates of people with disability in Australia compared to OECD countries must underscore efforts to improve employment outcomes for people with disability in the next Strategy. Even in the context of the COVID-19 pandemic, it is important to prepare people with disability for work and to improve systems, services and supports to assist people with disability in work, so that a generation of people with disability will not be further disadvantaged. The dangers people experience in closed systems, such as in some Australian Disability Enterprises (ADEs), will not diminish and without active intervention the number of

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[4] Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities (2019) in response to the List of issues prior to the submission of the combined second and third periodic reports of Australia [CRPD/C/AUS/QPR/2-3]. Compiled by the Australian Civil Society CRPD Shadow Report Working Group, July 2019.

[5] Children and Young People with Disability (2019), Time for change: the state of play for inclusion of students with disability, Results from the 2019 CYDA National Education Survey, p11

[6] Children and Young People with Disability (2019), op cit, p11

people with disability who will be subject to the constraints of closed systems is likely to increase.

Disability employment programs are poorly designed inhibiting people with disability from getting effective support to find and maintain a job. Challenges lie in the early streaming of school leavers into those deemed able to achieve open employment and those directed at supported employment, the current program structures that do not support sustained employment and the variable effectiveness of providers.

Key actions recommended for the next Strategy include the development and implementation of a person-centred system of employment support, designed around the individual with an automatic eligibility for a DES (with adjustments identified in the submission), an approach to enhance the effectiveness of employment providers and incentives to encourage the creation of employment opportunities targeted at people with disability by all governments.

Income support

Whilst many people with disability are frustrated about relying on the Disability Support Pension (DSP) when they have the ability and readiness to work, for many, the motivation to seek open employment is impeded by their perceived fear of financial insecurity associated with loss of the DSP, including the uncertainty of unskilled employment and the mutual obligation requirements related to the Newstart Allowance. This is especially relevant to people with psychosocial disability who have fluctuating capacity to work.

Disincentive to DSP participants from maximising their workforce participation include requirements to demonstrate 'continuing inability to work for at least 15 hours a week' in order to qualify for the DSP, the rate of reduction of DSP for every dollar earned and the suspension of the DSP for participants who work more than 30 hours a week. Scenario testing by the NDIS Actuary demonstrates that removing some of the DSP-related disincentives to employment is expected to result in a higher net revenue both for NDIS participants and government.

Key actions recommended for the next Strategy include a review of the disincentives in the income support system to maximise workforce participation of DSP recipients and the extension of safety net provisions for income security to NDIS participants.

Housing

The national crisis in affordable housing makes it very difficult for people with disability to find housing they can afford. These difficulties result from challenges in the private rental market, their lack of priority in social housing, the lack of requirements on developers that would foster more affordable housing and the lack of financing options that could encourage investors and families to contribute to the provision of affordable housing.

For people with challenges related to mobility, the constraints are even more significant as a result of the lack of mandatory minimum standards related to accessibility and a lack of action by the housing industry.

The lack of accessible affordable housing has profound impacts on people with disability. People enter and remain in inappropriate housing including residential aged care, there is a growth in demand for traditional shared living options when people would benefit from less restrictive options, families and carers remain out of the workforce, the costs of care and transport increase and people miss out in opportunities for work.

Many people with disability are not prioritised for social housing in the context of a national shortage of affordable housing. Many require accessible housing that incorporates design features that are not widely available. The Regulation Impact Statement (RIS) for the inclusion of minimum accessibility standards for all housing in the National Construction Code provides a unique opportunity for the Strategy to increase supply of accessible housing and this must be coupled with a reliable way for people requiring accessible housing to identify suitable properties.

Key actions recommended for the next Strategy include a commitment to significant growth in affordable, accessible housing targeted to people with disability, with all social housing built to Livable Housing Design Gold Standard (LHDG) and a significant increase in the supply of accessible housing.

Justice

People with disability face many challenges when in contact with the criminal justice system including difficulty understanding and exercising their rights and limited access to bail, diversionary orders, non-custodial sentencing options and parole. Within custodial environments, people with disability are vulnerable to abuse and to developing an entrenched propensity to reoffend. They also experience challenges in moving from the highly structured environment of custody to an unstructured environment in the community.

The NDIS takes a narrower view of its role than previous State and Territory Governments and under the interface principles, state justice departments are required to provide support for which they have little training or motivation.

People with cognitive impairment at risk of engagement with criminal justice systems require early intervention in schools and other services where children and young people show signs of becoming offenders, independent support in police interviews and criminal courts so that people with cognitive impairment are able to understand and exercise their rights, court diversion systems for young people and adults with cognitive impairment and enhanced practice in skill development correctional systems in working with offenders with intellectual disability.

Key actions recommended for the next Strategy require State and Territory Governments to develop and resource an infrastructure of services that support offenders with disability including justice advocacy services, diversionary programs for people with cognitive disability, intensive case coordination and clinical teamwork, additional support units in corrections facilities and psychological and other services in Juvenile Justice.

Domestic and family violence

Women with disability are often unaware of their rights and unable to access support in a timely way because information about sexual and safety rights is often not provided to people with disability and generic community information campaigns are not accessible to or targeted at women with disability. In addition, some women with disability have never accessed disability supports, having been denied access by partners and families as a form of control or even as assumed protective measures.

Supports and services across Australia vary widely. There is often however the common presumption that the victim survivor must leave the property with the shortage of responsive crisis accommodation making this a challenge for many women with disability.

Key actions recommended for the next Strategy include ensuring that the *National Plan to Reduce Violence Against Women and their Children* is inclusive of all forms of gender-based violence, regardless of the setting and the perpetrators of such violence; that gender-based violence services are inclusive of and responsive to women and girls with disability, and women with children with disability; that flexible support is increased; that the presumption that the victim survivor must leave the property is challenged and that barriers to crisis supported accommodation are removed. Additional resources are also required to support DPOs to develop and implement initiatives to address violence against women with disability.

RECOMMENDATIONS

Citizens with disability at the heart of the national disability strategy

System	Recommendations
Department of Social Services	Develop and implement strategies to support leadership of people with disability including support for DPOs to: • Facilitate peer networks that empower people with disability to become active citizens • Enable people to experience leadership in a safe space • Remove barriers and enhance opportunities to secure rights • Contribute to the development, implementation, monitoring and evaluation of the National Disability Strategy • Provide support for leaders and emerging leaders including coaching and mentoring opportunities, scholarships to attend mainstream conferences, formal leadership programs, a register of leaders with disabilities that can be used to develop the capacity of mainstream organisations Work across government departments to establish a leadership stream of people with disability together with the private sector, that would: • Consult with people with disability about specific enablers of leadership in the specific sector • Create opportunities for people with disability to engage and be meaningfully involved in the design and implementation of strategies at all levels.
National, State and Territory Attorney's General	Require all legislation to be reviewed through a lens that ascertains its impact on the participation and inclusion of people with disability.

System	Recommendations
Department of Prime Minister and Cabinet	Re-establish a National Disability Council to co-design the Strategy with the Commonwealth Government, and to provide advice at the national, state and local levels. Report to Parliament annually on the achievements under the National Disability Strategy. Include commitments of the National Disability Agreement into other Commonwealth and State Agreements (In line with recommendation of the Productivity Commission).
State and Territory Departments of Premier and Cabinet	Establish proactive Commissions for Disability Equality, similar to the Victorian Gender Equality Commissioner. Report to Parliament annually on the achievements under the National Disability Strategy. Strengthen State Disability Councils to contribute to the co-design State Disability Strategies.
Public Service Commissions	Establish and implement targets for the employment of people with disability.
All government departments	Co-design the development and implementation of the Strategy with people with disability at the national, state and local government levels including: - A resourced role for DPOs - The establishment of a reference group in each government department - Commitment to co-design government work that impacts on people with disability. Include requirements under the Strategy in KPIs of Departmental Head and senior executive staff. Establish and implement targets for the employment of people with disability including: - Mechanisms that support the employment and retainment of staff with disability - Preference contracts with and procurement from companies that employ people with disability Co-design strategies to improve responsiveness of government services with people with disability. Strategies include:

System	Recommendations
	• Auditing for barriers to support as the first step of service redesign to promote responsiveness • Understanding reasonable adjustment in service provision and what that means for specific departments and roles • Using people who use the service in processes to design adjustments • Training of staff is delivered by people with disability • Employing people with disability at all levels of the organisation • Having transparent processes in each department to solve problems and facilitate access for people with disability who experience challenges in using the service. In Ireland, for example, each government department has a visible contact person for people with disabilities wishing to access such services, and to support staff to provide services to people with disability. Create opportunities for real engagement with people with disability. Develop, resource and implement strategies to change attitudes that are well resourced, multifaceted, prolonged and work simultaneously at the personal, organisational and government levels. Develop, measure and report on outcomes and ensure improved monitoring, review and evaluation of the Strategy including: • Ensuring that all data collected is disaggregated by disability, disseminated and reported • Reporting on measures that reflect changes in outcomes for people with disability as well as measuring changes in culture and community attitudes • Developing and using key indicators that align with quality of life domains across all government departments to provide the basis for identifying need, allocating funding and resources and monitoring change over time • Using measures that are consistent with international measures and indicators used by OECD countries to track progress with other OECD countries
Local Governments	Require that local government partner with people with disability and their DPOs to strengthen the welcoming nature of communities.
Tertiary Education Sector	Require each field of study include a unit that examines the impact of professional practice on the participation and inclusion of people with disability.

Seamless interfaces

System	Recommendations
National Federation Reform Council (NFRC)	Develop mechanisms to ensure a collaborative and coordinated approach so that the individual is supported by a coherent set of supports <u>across</u> interfaces. Strategies that may facilitate a seamless approach include: • Commit to solve the challenges from the perspective of the individual not the perspective of the system • Address barriers to support rather than hinder disability in changing practice • Build bridges at systemic and local level • Authorise coordinated cross-sector approaches, providing resources to seed local initiatives of integrated support at the local level • Involve people with disability at all levels • Develop robust data • Involve local government • Develop a plan

Information, Linkages and Capacity Building

System	Recommendations
Department of Social Services	• Ensure effective cooperation and alignment between the work of the NDIA and DSS around setting ILC commissioning. • Ensure transparency about the process of developing the ILC investment strategy • Ensure lived experience input, collaborating closely with people with disability and the sector in determining ILC priorities, to benefit participants and non-participants and leverage Scheme priorities. • Establish robust evaluation frameworks and report on the outcomes of ILC.

Health

System	Recommendations
Services Australia	Review of Medicare items to ensure they provide the extra time people with disability need for accurate and respectful diagnosis and treatment and incentivize rather than penalise access to health.

System	Recommendations
	Examine the feasibility of a health profile (to complement e-health records and similar to a QANTAS profile) in which people with disability can outline information about disability support needs relevant for health professionals.
Australian Bureau of Statistics/ Australian Institute of Health and Welfare	Establish a national system of data collection and analysis on the health status of people with disability.
National, State and Territory Attorney's General	Establish a national system of review of deaths focused on both the health system and the disability support system.
State and Territory Governments	Establish mechanism for specialist consultancy support such as identified in this submission including specialised disability health teams and programs to enhance primary health care for people with disability. Establish a system of contact officers in hospitals to support responsive service provision for people with disability.
COAG Health Ministers Conference (or its equivalent)	Require all government health initiatives to consider what action is needed to make the initiatives work for people with disability. Implement a national system to ensure GPs offer comprehensive, high-quality, annual health assessments to people with disability. Fund of university-based centres of excellence.
Tertiary Institutions	Ensure pre-service training and ongoing professional development for health professions, including programs in the physical and mental health of people with disability and values-based training employing people with disability and family members as trainers. Require funders of research to ensure that research is inclusive of people with disability.

Early childhood

System	Recommendations
Commonwealth, State & Territory Governments	Consolidate and provide coordinated and additional resources to mainstream early childhood education and care settings for inclusion support and workforce capability support. Provide funding to early childhood education and care settings to ensure assistive technology and equipment needs can be met to support inclusion of all children.

Child protection

System	Recommendations
National Federation Reform Council (NFRC)	The National Framework for Protecting Australia's Children 2009-2020 is to be renegotiated shortly. The first plan under the next Strategy should focus on children with disability with strategies to understand the issues clearly and strengthen the whole of government response.
State & Territory Governments	Require child protection services to develop risk assessment tools that guide child protection workers to view parents in the context of supports. Develop protocols that require child protection agencies to refer an NDIS participant parent (or pregnant participant) back to the NDIA for an urgent plan review to meet expectations of the child protection agency. Require mainstream community, family support and health providers responsible for parenting programs to make reasonable adjustments to enable parents who have a disability to gain the core competencies required.

Families and carers

System	Recommendations
Commonwealth Government	Develop and resource a new National Carer Strategy to: • Increase resources to family and carer support to at least pre NDIS days • Provide a clear seamless pathway to support for carers in their own right.
State and Territory Governments	Increase resources to family and carer support programs.

Education

System	Recommendations
Department of Education, Skills & Employment	Develop a National Action Plan for Inclusive Education that includes a legislative and policy framework that fully complies with Article 24 of the CRPD.
State and Territory Governments	Develop and resource a state-wide plan of support for children and young people in education in the pandemic.
NDIS and State and Territory Education Departments	Clarify and resource the roles and responsibilities of the NDIS and mainstream education in support for children and young people being schooled at home in the pandemic

Employment

System	Recommendations
Department of Social Services / Department of Education, Skills and Employment	Develop and implement a person-centred system of employment support, designed around the individual. This includes automatic eligibility for a DES (with adjustments identified in the submission) so that NDIS participants of working age can use mainstream employment services charged with helping them to find and retain work. Enhance the effectiveness of employment providers
Commonwealth, State and Territory Governments	Implement incentives to encourage the creation of employment opportunities targeted at people with disability

Income

System	Recommendations
Services Australia	Review the disincentives of the income support system and maximise workforce participation of DSP recipients. Extend safety net provisions for income security to NDIS participants to extend their aspirations to open employment. This includes: • Review taper rates off the DSP • Publicise information about return to DSP for recipients who drop working hours or loose employment, and about the provisions for not having to reapply for the DSP

System	Recommendations
	• Secure automatic eligibility to a Health Care Card for NDIS participants (given Mobility Allowance is now part of the NDIS).

Housing

System	Recommendations
Commonwealth Department of Industry Science, Energy and Resources	Commit to significant growth in affordable, accessible housing targeted to people with disability. In order to increase the supply of accessible housing, require the inclusion of minimum accessibility standards for all housing in the National Construction Code recommending Governments and the Australian Building Code Board to: • Adjust the National Construction Code to set minimum mandatory accessibility standards, broadly reflecting the Livable Housing Design Gold Standard (LHDG) for all new Class 1a and Class 2 buildings.[7] • Explore the potential for a subsidy program to encourage availability of accessible rental properties[8] to be implemented over the next 10-15 years, while the stock of accessible housing grows. • Ensure the new accessibility housing standards are based on the current LHDG and not the diluted version, as described in the draft of proposed changes to the National Construction Code. • Initiate a pilot to make better use of the existing accessible housing stock using the existing infrastructure provided by the Housing Hub and/or Nest matching platforms.
State Housing Departments	Increase the supply of affordable housing targeted at people with disability. Ensure all social housing is built to Livable Housing Design Gold Standard (LHDG). Increase supply of accessible housing.

Justice

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[7] Op cit, Option 2 of the RIS
[8] Op cit, Option 5 of the RIS

System	Recommendations
COAG Justice Ministers (or equivalent)	Resolve issues of interface responsibilities between the NDIS and state justice and other agencies. Develop collaborative approaches to bridge interfaces in the best interest of participants.
State and Territory Governments	Develop and implement programs such as: • Justice advocacy services: providing support to people with cognitive impairment in police interviews and criminal courts. • Cognitive Impairment Diversion Program: providing short-term intensive casework into appropriate disability and other support and thereby enabling diversion from the criminal courts. • The case coordination and clinical teamwork of the former Community Justice Program: providing short-term specialist assessment and case coordination to facilitate access to the NDIS and other necessary services for people with serious histories of offending. • The State-wide Disability Service and additional support units in corrective services: aimed at ensuring the safety and meeting the support and program needs of prisoners with disability and people supervised by community corrections. • Psychological and other services in Juvenile Justice to meet the needs of young offenders with intellectual disability. Ensure people with disability, their families and carers are consulted and drive the implementation of the above. Ensure mental health and alcohol and other drug services are accessible and appropriate for alleged offenders with intellectual disability.

Domestic and family violence

System	Recommendations
State Domestic and Family Violence Systems	Ensure that the *National Plan to Reduce Violence Against Women and their Children* is inclusive of all forms of gender-based violence, regardless of the setting and the perpetrators of such violence. Ensure gender-based violence services: • Are inclusive of and responsive to women and girls with disability and women with children with disability

System	Recommendations
	• Build inclusive practice focusing on barriers to support rather than impairment. Expand the provision of Family Violence Flexible Support Packages. Challenge the presumption that the victim survivor with disability must leave the property. Remove barriers to crisis supported accommodation for women with disability and women with children with disability including ensure: • Accommodation services include disability accessible units • Alternate accommodation is available for women with adolescent sons with disability. Ensure disability training for all domestic and family violence workers is undertaken by people with disability who understand disability and family/domestic violence. Provide information in accessible languages, including easy English, audio and video. Adopt a consistent and comprehensive approach to data collection on people with disability escaping domestic and family violence.
Department of Social Services	Resource and support DPOs to develop and implement initiatives to address violence against women with disability. Adequately support organisations and networks of women with disability to engage in all initiatives to promote gender equality.
Department of Social Services & State and Territory domestic and family violence services	Establish mechanisms to fund collaborative programs that promote cross-sector learning and joint planning and provision of support. • Areas for joint learning include the nature of violence against women with disabilities, ableism, barriers to safety faced by women with disabilities, sexual and safety rights for women with disability • Joint planning and provision of support including collaboration in provision of flexible support especially where short-term accommodation is required.

1. Citizens with disability at the heart of the national disability strategy

For the National Disability Strategy to have an impact in enabling people with disability to become active citizens, the Strategy must:

- include mechanisms that facilitate leadership within government and by people with disability;
- strengthen accountability including robust data to measure outcomes;
- engage people with disability as active citizens;
- change community attitudes toward people with disability; and
- ensure seamless interfaces between the NDIS and other service systems.

Leadership

The Strategy requires real leadership across government if it is to inspire committed and resourced action across business, services and the community. The Strategy must also enhance leadership by people with disability so they can partner with government, business and community organisations to develop an inclusive society.

Leadership by people with disability

"Nothing about us without us"

The Strategy must strengthen the leadership of and by people with disability to ensure they are resourced to contribute to the evolution, design and implementation of an Australian society in which people with disability are active citizens. The Strategy must view a strong sector of DPOs as fundamental to supporting the voice and leadership of people with disability, resourcing DPOs to:

- facilitate peer networks that empower people to become active citizens;
- enable people to experience leadership in a safe space ;
- remove barriers and enhance opportunities to secure rights; and
- establish and support a register of leaders with disability that can be used to develop the capacity of mainstream organisations.

A strong sector of DPOs will provide a reference point for accountability of government and the community in the development, implementation, monitoring and evaluation of the Strategy; and will ensure a rich diverse voice into mainstream initiatives not directly related to people with disability.

Government support for a leadership stream of people with disability across government and the private sector would provide a vehicle for consultation about specific enablers of leadership in specific sectors and create opportunities for people with disability to be meaningfully involved in the design and implementation of strategies at all levels.

Strategies to strengthen the leadership of people with disability must be resourced by Government and could be used for coaching and mentoring to take up leadership positions in mainstream, community and private sectors, scholarships that enable people with disability to

attend mainstream conferences in which they can present papers and gain skills and enhance networks and formal leadership programs such as that provided by the Disability Leadership Institute, a professional hub for disability leaders, that provides coaching, networking and a range of resources to develop leaders with disability.

At the highest levels of government

Leadership in government is critical. With the review of the Disability Reform Council and consideration of future Ministerial structures, the Strategy will potentially be without leadership and oversight at the highest level. The early replacement of the decision-making structure will be critical to demonstrate an affirmation by governments to actively lead and contribute to effective governance structures at a time when various inquiries are highlighting systematic challenges.

Strategies that demonstrate commitment at the highest level of government include:

Annual report to Parliament

Delivered by the Prime Minister and the Premiers and Chief Ministers of each State and Territory on achievements under the Strategy,

Requiring all legislation to be viewed through a disability lens

The Strategy should require all legislation to be reviewed through a lens that ascertains its impact on the inclusion and participation of people with disability similar to the approach used by the Victorian Charter of Human Rights to review the impact of legislation on human rights lens in Victoria.

The establishment of proactive State Commissions for Disability Equality

At the national level, the Disability Discrimination Commissioner works to advance disability rights within a clear framework consistent with the UNCRP. No such role exists at the state and territory level where a role could be modelled on the Victorian Gender Equality Commissioner who is tasked with the implementation of new legislation promoting gender equity in the Victorian community and workplaces.

Disability Equality Commissioners should be located within Departments of Premiers and Cabinet to demonstrate the serious whole of government commitment to the strategy.

Establish employment targets related to people with disability

Government should model good practice in employment by requiring that public sector agencies employ people with disability (paying equitable wages), with targets reflective of the incidence of disability in the community. Obligations of this nature could replace current government preferential treatment of Australian Disability Enterprises (ADEs) and be included in government procurement and key funding contracts.

Possible approaches to increase employment participation of people with disability include proactive recruitment strategies, strategies that highlight people with disability as valued employees including, for example, that all MPs employ at least one person with disability or

have internship opportunities where people with disability work in the office of a politician. Scholarship programs that support people with disability gain the knowledge and skills they need to become leaders in their field and role models for other people with disability would be another important component. All such measures should be reportable.

All departments should have mechanisms that support and report on the employment and retainment of staff with disability.

Highlight planning around people with disability in emergencies

The 2019-2020 bushfires and the pandemic highlighted the increased risks faced by vulnerable groups including people with disability. The next Strategy must demonstrate its commitment by co-designing strategies that support people to be and feel safe.

Requirements in the procurement process

As well as preferencing the employment of people with disability, government procurement processes could also be used to favour companies that improve participation and inclusion of people with disability.

Accountability

The leadership stream of people with disability is the essential first step of ensuring the Strategy is co-designed, monitored, evaluated and accountable to people with disability.

Council recommends clear simple messages to underpin government accountability with mottos such as *We fund 'it' – what about you do 'it' for everyone,* asking departments to reflect on whether there are barriers to access and whether they are meeting their funding obligations while many people with disability have significant challenges in using their service.

Strategies to enhance accountability include:

Commitments of the National Disability Agreement into all Commonwealth–State Agreements

Council supports the proposal of the Productivity Commission into the National Disability Agreement that, in recognition of the cross-cutting nature of the National Disability Agreement and of the impact of agreements in health, education, housing etc on people with disability, that commitments and obligations of governments under the new National Disability Agreement should be reflected in the other Commonwealth–State Agreements (including National Partnerships).[9]

Co-design the development and implementation of the NDS with people with disability

There is currently no national body of people with disability tasked with the development, implementation and monitoring of national plans under the NDS and the role of state and territory disability councils is limited.

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[9] Productivity Commission (2019) *Review of the National Disability Agreement,* p10

Complementing a strong DPO sector discussed earlier, Council proposes targeted strategies to strengthen the voice of people with disability in the development and monitoring of the NDS at all levels. It is proposed that:

- Nationally: the re-establishment of a National Disability Council to co-design the NDS with the Commonwealth Government and to advise on strategies for the co-design of the Strategy at the national, state and local level.
- State and Territory: the strengthening of State Disability Councils to contribute to the co-design State Disability Strategies
- All national and state government agency to develop a Reference Group to guide the department in ensuring its service offerings are responsive to people with disability and that it is a model employer of people with disability. The Reference Group to be co-chaired by an executive member of the government agency and a senior staff member with a disability. State Disability Councils should be tasked with assisting state government departments to establish suitable membership and track the representative nature and effectiveness of departmental reference groups.
- Local Government: requirement that local government partner with people with disability and their DPOs to strengthen the welcoming nature of communities.

Government should commit to including the voice of people with disability in the development of all government work that impacts on people with disability. This includes National State and Territory Agreements, Disability Equality Commissions, Disability Discrimination Commissions and Disability Advisory bodies.

Develop, measure and report on outcomes

Government cannot be sure what was achieved in the first Strategy because there were no systematic steps to collect, disaggregate, disseminate and report on data that would establish a baseline and report on progress.

Council is pleased to see the commitment to improved monitoring, review and evaluation of the next Strategy. This requires the collection, dissemination and reporting on data that reflect changes in outcomes for example in employment, education, health, and social participation for people with disability as well as measuring changes in culture and community attitudes.

This will mean:

- ensuring that all data collected is disaggregated by disability, disseminated and reported;
- key indicators that align with quality of life domains must be developed across all government departments to provide the basis for identifying need, allocating funding and resources and monitoring change over time; and
- consistency with international measures and indicators used by OECD countries to track progress with other OECD countries.

Departmental Head responsible for outcomes resulting from improved service responsiveness

Responsibility for service responsiveness to people with disability should be reflected in KPIs of the Departmental Head and all senior executives.

Strategies that improve service responsiveness are co-designed with people with disability and include:

- auditing for barriers to support as the first step of service redesign to promote responsiveness;
- there is an understanding of reasonable adjustment in service provision and what that means for specific departments and roles;
- using people who use the service in processes to design adjustments;
- training of staff is delivered by people with disability;
- employing people with disability at all levels of the organisation; and
- having transparent processes in each department to solve problems and facilitate access for people with disability who experience challenges in using the service. In Ireland, for example, each government department has a visible contact person for people with disabilities wishing to access such services, and to support staff to provide services to people with disability.

Engagement

The Australian Law Reform Commission reported that *a root cause of social and economic inequality for people with cognitive disabilities is the lack of opportunity to have real and valued input into the development of policies, procedures and service design and the provision within government, service providers and the broader community.'*[10]

The Australian Government invited all Australians to have their say in the design and implementation of the National Disability Strategy, and it is critical that strategies give people with disability a real and equal 'voice at the table.' This involves the creation of real opportunities for engagement as well as support for participation.

Grass roots organisations such as DPOs have a critical role in supporting engagement. As discussed earlier in the submission, DPOs will provide a base of people with disability who will be supported to take forward views reflective of broader experience than their own to contribute to building a more inclusive community. Such organisations may have a role in auditing government, business and community organisations to underpin a more inclusive approach.

Changing attitudes

It is pleasing to see an increased focus on community attitudes in the new Strategy with a commitment to facilitate and foster ongoing attitudinal change to harness the rich contribution that people with disability can make to society. Work by Fisher and Purcal[11] investigating

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[10] Voice and the Table Voice at the Table Link
[11] Fisher, K, Purcal, C, (2016) Policies to change attitudes to people with disabilities, Scandinavian Journal of Disability Research Accessed Link to Paper 25 September 2020.

policies that change attitudes to people with disability found that attitudinal change is more likely to be successful when efforts are focused at the individual, organisational and governmental levels simultaneously and over an extended period of time. [12]

Whilst there has been limited evaluation of programs and policies to change attitudes, Fisher and Purcal conclude that factors associated with effectiveness include:

- policies include direct positive contact with people with disability;
- information and awareness campaigns;
- education and training about disability e.g. in teacher and employer training; and
- legislation to enforce anti-discrimination measures.

Furthermore, research evidence indicates that effectiveness is enhanced when direct positive contact is combined with information; when information, awareness, education and training programs are multi-faceted and prolonged and where the approach is well resourced.

For example, countries where attitudes to inclusion of children with disability have changed the most have introduced multiple interventions at all three levels, including mandating inclusive education policies (Government level), teacher and student training, support and contact (Organisational level) and community media (personal level) which exposes children, families and teachers to positive portrayals of people with disability.[13]

Tertiary studies have an important role to play in changing attitudes to people with disability. A significant proportion of fields of study prepare students for work that will have an impact on people with disability. A requirement that each field of study include a unit that examines the impact of professional practice on the participation and inclusion of people with disability would contribute to a more inclusive society.

Creating real opportunities for engagement

Government, businesses, service providers and community organisations need to be accountable for creating opportunities for people with disability to contribute. The increased focus on community attitudes of the next Strategy is a first step. Additional steps involve assisting those in power to understand the benefits of consumer participation and thereby commit to the strategies required to bring the benefits to fruition.

Voice at the Table identifies benefits for government and organisations of consumer participation as listening to the experts about their lived experience, insights into the perceptions, experiences and barriers faced by service users, new ideas about ways of doing things, higher satisfaction scores, more inclusive practices. The benefits of consumer participation to people with disability include sharing ideas, challenges and expertise, feeling valued, influencing policy and making change, increased confidence, better quality services and ongoing opportunities.

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[12] Fisher, K, Purcal, C, (2016) Personal level policies are directed at changing attitudes of individuals toward people with disability and involve a combination of information, education, training, positive portrayal of people with disability and supported opportunities for contact. Organisational level policies attempt to improve attitudes in life domains such as education, employment and health using training, complaints mechanisms and targeted information programs that seek to change the behaviour and attitudes of people without disability while simultaneously empowering people with disability to claim their rights. Government level policies attempt to influence attitudes by mandating behaviour change working on the premise that human rights not enforced are merely good ideas.

[13] Fisher, K, Purcal, C, (2016) p10

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2. Seamless interfaces

In the context of the promise that the new Strategy will emphasise a whole of society approach to implementing disability inclusive policies,[14] it is unacceptable that individuals with disability will have their need for critical support caught in territorial battles within and between governments. People with disability have little or no interest in territorial battles. They do not want mini disability programs within mainstream agencies. They want to access services and supports in the same way as other Australians and hence implicitly expect collaboration between different government agencies as appropriate.

The working groups that designed the Principles to Determine the Responsibilities of the NDIS and Other Services Systems (the interface principles) anticipated the complexity of navigating multiple service systems. The interface principles require each *system to work closely at the local level to plan and coordinate streamlined services for individuals requiring support from both systems, recognising that support may be required at the same time or through a smooth transition from one to the other.*[15] By and large systems have not been successful in implementing the intent of this principle. This should not be surprising when each system is required to coordinate support up to the limit of their responsibility and no-one is authorised to coordinate support across the interface.

A seamless mechanism to overcome interface challenges is essential and should be developed in the context of the Productivity Commission recommendation of a review of roles and responsibilities in the National Disability Agreement to reflect contemporary disability policy, reduce uncertainty and address gaps. The new Strategy must facilitate a collaborative and coordinated approach <u>across</u> the interface.[16]

A person-centred system proposed in the Discussion Paper requires a seamless mechanism to overcome interface challenges because as Robinson demonstrates, the number of interfaces a person may need to negotiate is cumulative,[17] their impact amplifies over time and individuals (or their case managers or support coordinators) cannot negotiate interface challenges alone at the local level.

What is required is a collaborative and coordinated approach to ensure an individual is supported by a coherent set of supports <u>across</u> the interface and early insights that this objective is not being met.

Statement of the problem

Even though mainstream services should be providing equitable services to all Australians, they tend to operate in silos without the motivation, culture, knowledge and skills to ensure their core business is welcoming to people with disability. Services that support people with disability tend to have very limited capacity to respond to the range of challenges people may experience. In the siloed approach, people with disability risk either not having their needs

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[14] DSS (2020) National Disability Strategy Position paper, p2

[15] Principles to Determine the Responsibilities of the NDIS and Other Services Systems

[16] Productivity Commission (2019) Review of the National Disability Agreement, p2

[17] For example, a parent with an intellectual disability may have to negotiate challenges at the interface with health and child protection at the time of the birth of her child with interfaces with family support and early childhood added soon after.

met or receiving an inappropriate response, such as interventions by statutory child protection services, due to lack of available alternative support.[18]

In a siloed approach, challenges arise from:

- a disconnect between mainstream and disability policy and service delivery;

- a lack of confidence and skill of workers in mainstream service systems to work with people disability;

- gaps in services and systems in the context of constrained resources and thin markets; and

- lack of integration and coordination across sectors and services, especially for people with complex sets of needs across multiple sectors, compounded by fragmentation of service types. [19]

Lessons from research

The Social Policy Research Centre (SPRC) conducted a review of the implementation of the National Disability Strategy 2010-2020 on behalf of the Department of Social Services.[20] Positive examples of the Strategy's implementation included the active participation of people with disability, cooperation across governments, and partnerships between local government, community organisations and business. The report discussed the importance of:

- facilitating the participation of people with disability at all levels of policy design and implementation;

- providing local government with resources and integrating their activities with measures at other levels of government;

- resourcing and supporting grassroots initiatives and facilitating opportunities for future partnerships with government and business to enhance the reach of these initiatives; and

- linking localised initiatives to broader system changes by generating evidence of effectiveness and raising the profile of the Strategy in governments and the wider community.

The SPRC report also emphasised the importance of facilitating cooperation and collaboration between government portfolios and levels of government and with community organisations, disability representative organisations, business and services.

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[18]Robinson, S., Valentine, K., Newton, B. J., Smyth, C., & Parmenter, N. (2020). *Violence prevention and early intervention for mothers and children with disability: Building promising practice* (Research report, 16/2020). Sydney: ANROWS. P5

[19] Op cit. p14

[20] Davy, L., Fisher, K.R., Wehbe, A., Purcal, C., Robinson, S., Kayess, R., Santos, D. (2019). *Review of implementation of the National Disability Strategy 2010-2020: Final report. (SPRC Report [4/19)*. Sydney: Social Policy Research Centre, UNSW Sydney. http://doi.org/10.26190/5c7494b61edc4

Other research into challenges faced by people with disability in using services provided by mainstream agencies[21] emphasised the importance of focusing on barriers to support rather than impairment because barriers to support could inform positive practice principles of effective responsive support. Positive practice principles identified included timely responses and scaffolded planning, personalised and flexible support, building and sustaining local sector relationships, improving service coordination and building cultural safety with Aboriginal families. The research recommended strengthening practice through building workforce capacity and training based on principles of positive practice.

Features of good practice

Good practice with people with disability working across interfaces centre around: [22]

- fundamentals of good practice based on good or emerging practice in the specific field of working with people with disability in the mainstream environment;

- cross-sector collaboration and cross-sector cultural awareness training;

- intensive case management that can incorporate aspects of community development and outreach. Whilst all interface principles conclude with a statement of intent to coordinate streamlined care, [23] no one system offers a holistic approach; both case manage up to and not across the interface;

- accessible information and online resources, which provide information and access to support, including peer support and community education; and

- empowerment and social support.

Commitment to put people with disability at the centre

The Productivity Commission recommended reorienting the NDA to a person-centred agreement that has at its core the individual needs, rights and aspirations of people with disability, as well as the needs of families and carers. [24] The Productivity Commission argued the NDA needs to be reconceptualised as an agreement that interacts with all mainstream service systems and other agreements, similar to the approach used for the Indigenous Agreement, with commitments and obligations of governments under the new NDA reflected in other Commonwealth-State and Territory agreements (including National Partnerships). [25]

This reconceptualization could put people with disability at the centre when developing solutions at the interface, providing leadership that the best interest of the individual should not be compromised in the inter-governmental battles over funding and/or accountability.

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[21] Robinson, S., Valentine, K., Newton, B. J., Smyth, C., & Parmenter, N. (2020). *Violence prevention and early intervention for mothers and children with disability: Building promising practice* (Research report, 16/2020). Sydney: ANROWS.

[22] Op cit. p6

[23] *The NDIS and the named mainstream system will work closely together at the local level to plan and coordinate streamlined care for individuals requiring both services recognising that inputs may be required at the same time or that there is a need to ensure a smooth transition from one to the other*

[24] Productivity Commission (2019) Review of the National Disability Agreement, p10

[25] Productivity Commission (2019) Review of the National Disability Agreement, p11

Mechanisms to ensure interfaces support people with disability

A mechanism that ensures systems support people with disability when their needs for support cross sector boundaries should:

Commit to solve the challenges from perspective of the individual not the perspective of the system

A commitment to solve challenges from the perspective of the individual not the system would acknowledge that top down approaches don't work in addressing challenges faced by people with disability and that person-centred systems should start with the individual and identify, plan, coordinate and deliver an integrated package of support from both systems.

Address barriers to support rather than disability in changing practice

A co-designed approach is critical to understanding and effectively removing barriers.

Build bridges at systemic and local level

There are multiple elements of bridge building. At the national level, until recently, the Disability Reform Council provided the bridge across government in relation to disability policy. Leadership derived from a strong effective and enduring governance process is required.

The Interface Principles call for the NDIS and other service systems *to work closely together at the local level to plan and coordinate streamlined services recognising that both inputs may be required at the same time or that there is a need to ensure a smooth transition from one to the other*. The challenge is that an NDIS support coordinator is required to focus on disability related supports and case management in mainstream systems focuses on the services for which the mainstream is responsible. The introduction of Justice Liaison Officers (JLOs) by the NDIS as a single point of contact for workers within state and territory justice systems to coordinate support for NDIS participants in youth and adult justice systems is an important step that needs to be evaluated.

Skill building in workers and organisations with a focus on barriers to support rather than on disability [26] is important if mainstream agencies are to provide a confident and appropriate response to the needs of people with disability.

Finally, practice principles that underpin mainstream approaches should include timely responses and scaffolded planning, personalised and flexible support, building and sustaining local sector relationships, improving service coordination and building cultural safety with Aboriginal families.

Authorise coordinated cross sector approaches

Complementing a more holistic approach to support across interfaces, there is a role for coordinated cross sector approaches in which each agency has resources available to seed local initiatives that must be evaluated for emerging good practice.

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[26] Robinson, S., Valentine, K., Newton, B. J., Smyth, C., & Parmenter, N. (2020). *Violence prevention and early intervention for mothers and children with disability: Building promising practice* (Research report, 16/2020). Sydney: ANROWS.
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Involve people with disability at all levels

All agencies need strategies to ensure an appropriate proportion of staff, including at senior level, and members of Boards are persons with disability. In addition, all need effective approaches of co-design for the development of service design and delivery. Partnerships with Disabled Persons Organisations will be important to enable government departments to identify barriers, design solutions, monitor progress and evaluate the impact of solutions.

Develop robust data

Little data is collected and published on the experience and outcomes of people with disability in mainstream services. Government must require the development and implementation of qualitative and quantitative measures tied to the same measurement and reporting metrics for other demographic characteristics on the experience of people with disability across all programs.

Involve Local government

In areas of where government, non-government and businesses contribute to the active participation and inclusion of people with disability, the role of local government should be considered in resourcing and supporting grassroots initiatives and facilitating opportunities for future partnerships to enhance the reach of these initiatives. The use of local government Disability Advisory Committees could be instrumental.

Develop a plan

A goal without a plan remains a wish. The NDS provides the high-level plan. Plans at state and local levels are essential to drive improvements to services, systems and data to increase awareness of, and better respond to, people with disability through the key focus areas of raising awareness, building sector capacity and capability, implementing practical responses and building the evidence. A similar set of expectations on non-government community services would enhance responsiveness.

Case study

Rehabilitation for people with Acquired Brain Injury (ABI) provides a case study of challenges at the interface of the NDIS and health systems for participants in need of person-centred seamless disability and rehabilitation support.

A recent study by Young People in Nursing Homes National Alliance[27] documented the service fragmentation and unnecessary administrative overlays that characterise the current system of rehabilitation for people with ABI. An effective rehabilitation model would be characterised by a partnership of the major stakeholders including acute and community based-health providers.[28] The study found that '*while there are some imperatives to improve service continuity, address workforce issues and clarify roles and responsibilities, many of the*

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[27] Young People in Nursing Homes National Alliance (2020), NSW Strategic project – capacity building for mainstream services and acquired brain injury, Final Report

[28] Costa, B & Gibson, K (2017) *Rehabilitation Models: A scoping review. Alternative rehabilitation models and frameworks for clients with traumatic and orthopaedic trauma*, Melbourne Institute for Safety, Compensation and Recovery Research, Melbourne: 14.

underlying problems raised through the project were a result of poor governance and the absence of a consciously designed service system.'[29]

The study described a common mistake of those seeking to collaborate arising from the assumption of common understandings of practice and of the reasons for collaboration without taking account of the way in which practice across systems had changed as a result of budgetary and time constraints. The biggest barrier to successful outcomes for participants was situated in the gulf between health and NDIS practice, a location in which competent and skilled service coordination should be the norm. Policy leadership and a demonstration of cross program collaboration from government agencies was seen as a precondition to collaboration being adopted in the service system.[30]

Reflecting the evidence of the literature review commissioned as part of the study, the report concluded that, because of the highly individualised nature of the impact of ABI, it is not feasible to create a linear service pathway across the ABI system, but required a highly capable and well networked system that enables the concurrent delivery of services from different programs.[31] The current unresolved understanding of responsibilities of the NDIS and health have thwarted the cross system collaboration required to enable people with ABI to get the rehabilitation they need to increase independence and reduce the long term need for care and support.

3.   Information, linkages and capacity building

The ILC Policy Framework articulates the rationale for the ILC:

> *A social insurance model invests in formal, disability-specific support to reduce the lifetime cost of disability, at both the population level and individual level. However, a system that responds only to an individual's need is not enough to ensure societal change in inclusion, access and equity of people with disability. Investment in community education, broad-based interventions and capacity building and supports for carers and families is needed. This investment sustains and strengthens informal support and promotes the social and economic inclusion and meaningful participation of people with disability.[32]*

This section will outline why the ILC is critical for positive outcomes for participants and the sustainability of the Scheme.

The importance of the ILC

4.3 million Australians have a disability but only about 500,000 (those with a permanent and significant disability) are eligible for the NDIS. If the gap in wellbeing between eligibility for the NDIS and non-eligibility is significant, there will be significant pressure for those deemed ineligible to enter the Scheme. A seamless interface is thereby required and can be facilitated

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[29] Young People in Nursing Homes National Alliance (2020), P42

[30] Young People in Nursing Homes National Alliance (2020), P11

[31] Young People in Nursing Homes National Alliance (2020), p42

[32] ILC Policy Framework p3

by the provision of information, linkage and capacity building services for ineligible people with disability to assist them to access the mainstream and community service support in the community.

The National Disability Strategy is one important vehicle to support mainstream and community services to meet their obligations to enable people with disability to access services to which they are entitled. Through the ILC, the NDIS had responsibility for building the capacity of individuals with disability, building their competence and confidence to use mainstream services and actively participate in community.

Core ILC responsibility for non-participants includes the provision of information and referral and capacity building to be more independent and more engaged socially and economically. ILC support that benefits non-participants must:

- provide information and referral to mainstream and community services;
- support community and mainstream organisations to be more welcoming;
- build their confidence and competence to lead rewarding lives in the community; and
- reduce pressure to enter the Scheme because they can get the support they need in the community that is more responsive as a result of ILC activity.

The ILC must also provide support for participants. Provision of ILC support for participants:

- reduces the demand for reasonable and necessary support. Where individual capacity building activities are available via block funded grants to community organisations, participants will be able to get support in a more cost-effective way;
- maximises participants' access to mainstream, community and informal supports because the community capacity building activities of the ILC will assist mainstream services to adjust their processes and be more welcoming to people with disability; and
- makes supports more effective at helping people achieve their goals. For example, a fitness goal is more likely to be achieved if funded support to use gym equipment is complemented by an inclusive gym community or a friend for companionship and motivation.

Another core responsibility of the ILC was to build the capacity of mainstream and community services to welcome people with disability. Without this, the Scheme is trying to change the systems one person at a time and is sending non-participants into an unresponsive environment. Whoever commissions ILC services will have increased capacity to influence the delivery of supports at a systemic level.

Council shares the concerns raised by the disability community and DPOs about ILC being removed from NDIA, due to the risk of disconnection between ILC and NDIA priorities and potential impact on outcomes for people with disability. Council believes that, for the ILC to produce the desired outcomes under the administration of DSS, there should be a strong focus on alignment between NDIA policy work and sustainability goals, and the priorities for commissioning and tendering for ILC, with effective cooperation between both DSS and the NDIA. .

The need for strong collaboration between DSS and the NDIA

The NDIA has deeper connections to people with disability and communities

ILC will only be effective if it complements but does not substitute for individual and mainstream services. Its effectiveness is weakened if it substitutes for either.

The NDIA has data on all participants, their goals and service utilisation giving a clear picture of demand and gaps in supply from specialist disability, mainstream and community services. It has links to services and supports of an operational and practical nature, not just policy, and therefore is best placed to know what is required, target provision and review the efficacy of local initiatives.

The NDIS has a range of advisory structures that ensure decisions are participant focused. The NDIA has been able to leverage the Council as a high-level source of advice about priorities that will impact the lives of people with disability most directly. For example, the Council prepared advice to the NDIA Board in relation to participants who are parents. This led to work within the NDIA to improve NDIA practice and to make representation to ensure more responsive mainstream service provision so that a future generation of children stolen from people with disability is averted. The enhanced NDIA practice and the requirements placed on mainstream services require national funding to small local organisations to support participant parents to grow healthy families and to support mainstream organisations to target their support effectively. Under NDIA auspice, this newly identified need is more easily prioritised and actioned than would be the case when the ILC is under the auspice of DSS.

Importantly though, the Council is not the only consultation mechanism within the NDIA. The introduction of a Participant Advocacy stream within the NDIA shows a commitment to cohesive, ongoing engagement with participants. By contrast, DSS currently lacks a clear structure for embedding the voices of people with disability to drive the development and prioritisation of ILC commissioning towards rights-based frameworks informed by lived experience.

ILC isolated from the NDIS strengthens the divide between participants and non-participants and increases pressure to enter the Scheme

A clear link between ILC and the NDIS ensures the Scheme is seen as a vehicle of support for all Australians with disability, with most people having access to information, referral and support from community organisations and a smaller number becoming participants eligible for individual packages of reasonable and necessary support.

Disconnection between the ILC and the NDIS may also negatively impact on participants exiting the Scheme, who need community and mainstream supports strengthened by ILC. Any processes that inhibit smooth transitions out of the Scheme pose risks to the sustainability of the NDIS, a significant concern to all.

There is a risk that under DSS auspice, ILC services will develop for only non-participants obviating the benefits that derive from participants and non-participants joining together. For example, peer networks auspiced by DPOs are a cost-effective strategy to build insights,

confidence and emotional support for all people with disability (participants and non-participants) to live the lives they want.

Risks to Scheme sustainability

NDIA decision making about priorities for limited resources derives from understanding of actuarial data, barriers experienced by participants, connections to community and links with providers and community organisations. This information must be considered by DSS when targeting ILC funding to complement individualised services that will enhance participant's ability to reach their goals. Without this, there's a risk that the NDIS will need to provide all capacity building support, posing a risk to Scheme sustainability.

Recommendations for the National Disability Strategy

- Ensure effective cooperation and alignment between the work of the NDIA and DSS around setting ILC commissioning.
- Ensure transparency about the process of developing the ILC investment strategy
- Ensure lived experience input, collaborating closely with people with disability and the sector in determining ILC priorities, to benefit participants and non-participants and leverage Scheme priorities.
- Establish robust evaluation framework and regular reporting on the outcomes of ILC.

4.   Health

Introduction

There are structural and systemic differences between health and disability that impede the responsiveness of the health system to support people with disability and often make it challenging for people with disability to access health services.

Fundamentally different paradigms underpin the health and disability systems. The health system is based on the medical model where episodes of ill health are treated in a curative approach that potentially throws poor light on people with disability. The disability system of the NDIS is based on the social model of disability where disability is seen as the result of the interactions between people living with impairments and environments filled with barriers.

Different cultures differentiate the two systems. The health system embraces speed and turnover as the cornerstone of an efficient health system while the disability system embraces relationship and continuity as fundamental to quality care and support. The systems are also differentiated by their access to power with the health system usually privileged with identified ministers holding cabinet positions in all jurisdictions and the disability system relying on a junior portfolio to prosecute its case.

Evidence of health inequalities makes it clear that the Australian health system is failing people with disability and access to health services is the threshold issue for the National Disability Strategy in health. Acknowledgement by all jurisdictions of the failure to provide equal access to primary and tertiary health services to people with disability would be a first step equalising the health outcomes of Australians with and without disability.

Health inequalities

Inclusion Australia documents the stark health inequalities experienced by people with intellectual and cognitive disabilities when compared with the general population:[33]

- 2.5 times the number of health problems

- 38 to 53 percent potentially avoidable deaths compared with 17 percent for the general population

- Early indications of future increased ill-health such as obesity and psychiatric disorder

- Under-diagnosis of chronic and acute health conditions that can lead significant functional impacts, potentially requiring increased use of disability services

- Higher rates of potentially modifiable cardiometabolic risk factors

- Under-representation of consultations with GPs addressing physical and preventative health issues

- Significantly less likely to be prescribed preventative health medications

- Higher prescription of psychotropic medication, even after allowing for elevated incidence of mental illness

- Double the usage of emergency departments and hospital admissions, with each admission costing twice as much

- Much higher rates of potentially preventable hospitalisation

- Five times more likely to experience mental health admissions of over a year, and three times as likely to be admitted more than three times a year

- 1.6 times more face to face contacts with community mental health services, and each contact is 2.5 times longer

- Die many years earlier, 27 years in one large Australian study.

The National Health and Hospitals Reform Commission documented similar "stark health inequalities"[34] and identified contributing factors including:

- Diagnostic overshadowing: the assumption that symptoms are part of a person's intellectual disability rather than a health condition that requires treatment

- Workforce challenges including inadequate workforce training on communicating with and addressing complex health care needs of people with intellectual disability

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[33] Trollor J, Srasuebkul and Howlett S (2017) and Office of the Public Advocate (Qld) 2016, Upholding the right to life and health: a review of the deaths in care of people with disability in Queensland www.justice.qld.gov.au/__data/assets/pdf_file /final-systemic-advocacy-report- deaths-in-care-of-people-with-disability-in-Queensland-February-2016pdf.

[34] National Health and Hospitals Reform Commission (2008) A Healthier Future for All Australians, Interim Report, pages 54-55.

- The lack of targeting of people with intellectual disability in health promotion and prevention strategies

- Inadequate uptake of Medicare annual health assessments

- The lack of societal value attached to people with intellectual disability

- Communication challenges between health professionals and people with intellectual disability

- Inadequate focus on healthy lifestyles and promoting good health in disability support services

- Poverty and other areas of social disadvantage.

The low level of training on the health of people with intellectual disability in university medical and nursing schools also contributes to uninformed practice with the median of 2.6 hours' compulsory content across 12 medical schools (with one university standing out with 12 hours)[35] and no intellectual disability content in 52% of nursing schools and very limited content overall.[36]

NDIA actuarial data

People with disability generally rate their health as poorer than other Australians,[37] and this holds true for NDIS participants. 68.2% of the 15-24 cohort and 46.3% of the 25-64 cohort rated their health as good, very good or excellent, compared to 91.9% and 86.6% of Australians of the same age.[38] Whilst some of the differential self-assessment will be disability related, some will certainly result from missing out on preventative measures.

NDIS participants also express lower overall life satisfaction than the general population. When asked to think about their life now and in the future, on a seven-point scale from "delighted" to "terrible", 41.5% of the 15-24 cohort and 44.2% of the 25-64 cohort said they felt either "delighted", "pleased" or "mostly satisfied", compared to 78.3% of Australians aged 18 to 24 and 77.0% of Australians 25-64.[39]

NDIS participants experience increased levels of psychological distress than the general population with 90% of female participants and 87% of male participants reporting moderate, high or very high risk of psychological distress, compared to 38% of the female Australian population and 34% of the male Australian population.

NDIS participants are also more likely to go to hospital than Australians generally. 28.7% of 15-24 cohort and 42.5% of 25-64 cohort had been to hospital in the last 12 months, compared to 7.9% of Australians aged 15 to 24 and 11.6% of Australians aged 25–64.[40] Moreover, 51.3%

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[35] Trollor J, Ruffell B, Tracy J, Torr J,Durvasula S, Iacono T, Eagleson C and Lennox N, Intellectual disability health content within medical curriculum: an audit of what our future doctors are taught bmcmededuc.biomedcentral.com/articles.

[36] Trollor J, Eagleson C, Turner B, Salomon C, Cashin A, Iacono T, Goddard L and Lennox N (□□□□) Intellectual disability health content within nursing curriculum: an audit of what our future nurses are taught www.sciencedirect.com/science/article/pii/

[37] Australian Institute of Health and Welfare (AIHW) (2018) Australia's Health 2018.

[38] ABS National Health Survey (NHS) 2017-18.

[39] ABS General Social Survey (GSS) 2010. For GSS 2014 the question changed from using seven descriptive categories to a rating on a 0 to 10 scale.

[40] ABS Patient Experience Survey (PES) 2018-19

of 15-24 cohort and 56.7% of 25-64 cohort who had been to hospital have had multiple visits, compared to a population figure of 21.8% for Australians aged 15 to 24 and 26.3% of Australian 25-64.[41]

The hospital data requires further exploration to unpack its complexity and understand the impacts on overall health outcomes. Higher than anticipated hospital admissions potentially reflect unplanned admissions where emergency departments (ED) are viewed as a viable option when participants do not have a GP or the GP is not available. Challenges in communication in EDs lead to the person being admitted, not receiving a well-informed diagnosis and treatment and hence requiring multiple admissions or experiencing avoidable harm. Preventative health screening and regular GP visits are more likely to lead to planned admissions in which the hospital is better placed to understand and respond appropriately to the health needs of the person.

31.0% of the 15-24 cohort and 34.5% of the cohort 25-64 said they had experienced some difficulty in getting health services. The most common reason cited was access issues (10.0% for cohort 15-24 and 9.7% for 25-64 cohort), however 6.4% of 15–24 cohort and 5.7% of 25-64 cohort said it was because of the attitudes and/or expertise of health professionals. Other factors associated with access difficulties include being of indigenous or CALD background, living in a more remote area and having lower level of function where attitudes / expertise of health professional and lack of support also feature.

Whilst many states and territories have taken positive steps to address issues that underpin health inequalities, more is required.

Key issues

Challenges in accessing health services

NDIA data that attitudes/expertise of health professionals is perceived as a barrier to accessing health services reflects the challenges experienced by mainstream health professionals and systems in diagnosing and treating with people disability. Medical consultations for people with disability may require additional time and the payment schedules are a disincentive to outreach to ensure people to access health services.

Women with disability face specific challenges in accessing screening for women's health issues. Suitable equipment is often not available for breast screens and many women with disability miss out on pap smears, some prevented from participating in screening by family and others miss out because they are not notified.[42]

The Medicare item for annual health assessments for people with intellectual disability is an important national step toward addressing health inequalities but a review of Medicare for people with disability is required to reduce disincentives to informed diagnoses and treatment. Systemic capacity building strategies such as the establishment of specialist intellectual

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[41] BS Patient Experience Survey (PES) 2018-19.
[42] The electoral roll is used as the data base for notifications and some NDIS participants are not on the electoral roll.

disability health teams[43] and the Intellectual Disability Network in NSW's Health Agency for Clinical Innovation[44] are required nationally.

People with disability report frustration at having to identify and explain their disability and support needs with each health or hospital contact. A health profile (similar, for example, to a QANTAS profile that complements the E-Health record) could outlines information relevant for a health professional to know and assist all parties.

Support in hospital

Study by Bigby et al into support for people with intellectual disability and cognitive impairment in hospitals identified a range of promising practices that are recommended to guide the development of hospital practices to improve the care experiences and health outcomes of people with cognitive disabilities. The practices are described as 'serendipitous and uneven' and thereby not recognised, shared or taught. The urgent need for action is strengthened by the study's documentation of 'an exceptional hospital encounter of a patient with cognitive disability who remained in hospital 131 days after she had returned to her pre-admission health and functional status'[45] demonstrating the economic and human cost of failures to manage complex discharge and decision-making issues for a person with cognitive disability.

A contact person who assisted people with disability and hospital staff to respond most effectively to a person's disability related needs is likely to improve the responsiveness of the health system.

Slow stream rehabilitation

The challenges related to slow stream rehab, where a collaborative approach between the NDIS and health are required to deliver concurrent delivery of services from different programs, are discussed in section 2. The biggest barrier to successful outcomes for these participants was situated in the gulf between health and NDIS practice, *a location in which competent and skilled service coordination should be.*[46] The highly individualised nature of the impact of ABI required a highly capable and well networked system that enables the concurrent delivery of services from different programs was required.[47] The current understanding of responsibilities of the NDIS and health however thwart the cross-system collaboration required to enable people with ABI to get the rehabilitation they need to increase independence and reduce the long term need for care and support.

Data

There is a need for better data to inform health practice of people with disability and this requires systematic steps to collect, disaggregate, disseminate and report on data that would establish a baseline and report on progress.

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[43] that provide consultancy support and build capacity of the local health district

[44] that produces educational resources

[45] Bigby, C., Douglas, J., & Iacono, T. (2018). *Enabling mainstream systems to be more inclusive and responsive to people with disabilities: Hospital encounters of adults with cognitive disabilities*. Report for the National Disability Research and Development Agenda. Melbourne: Living with Disability Research Centre, La Trobe University. P6

[46] Young People in Nursing Homes National Alliance (2020), NSW Strategic project – capacity building for mainstream services and acquired brain injury, Final Report

[47] Young People in Nursing Homes National Alliance (2020), p42

Recommendations for the National Disability Strategy

Commonwealth and State and Territory Governments must commit to improve the capacity of the health system to respond to people with disability. Building on strategies identified by Inclusion Australia, the NDS must:

- Review Medicare items

    o Review of Medicare items to ensure they provide the extra time people with disability need for accurate and respectful diagnosis and treatment and incentivize rather than penalise access to health.

- Establish specialist consultancy support

    o Each state and territory to establish a network of specialised disability health teams through local health districts

    o Each primary health network to have a program to enhance primary health care to people with disability

- Authorise a coordinated approach

    o COAG Health Ministers Conference or its equivalent must require all government health initiatives to consider what action is needed to make the initiatives work for people with disability and must report on KPIs related to responsiveness of initiatives to people with disability

    o A national system to ensure GPs offer comprehensive, high-quality annual health assessments to people with disability

- Train health professionals

    o Funding of university-based centres of excellence

    o Specialist recognition and training programs in the physical and mental health of people with disability

    o Values based training for all health professionals – both in tertiary education and ongoing with people with disability and family members employed as trainers.

- Research

    o A requirement on funders of research to ensure that research is inclusive of people with disability

- Collect and analyse data

    o The establishment of a national system of data collection and analysis on the health status of people with disability and a national system of review of deaths focused on both the health system and the disability support system

5.   Early childhood

Introduction

Inclusion is now recognised as an essential arm of early childhood intervention with 2 of the 8 best practice principles[48] focusing on the importance of:

- Inclusive and Participatory Practice: that recognises that every child regardless of their needs has the right to participate fully in their family and community life and to have the same choices, opportunities and experiences as other children. All children need to feel accepted and to have a real sense of belonging. Children with disability and/or developmental delay may require additional support to enable them to participate meaningfully in their families, community and early childhood settings. and
- Engaging the Child in Natural Environments: that promotes children's inclusion through participation in daily routines, at home, in the community, and in early childhood settings. These natural learning environments contain many opportunities for all children to engage, participate, learn and practise skills, thus strengthening their sense of belonging.

The interface principles indicate that the mainstream early childhood education and care sector is responsible for meeting the education and care needs of children with a development delay or disability including through reasonable adjustment; inclusion supports to enable children to participate; and building the capacity of early childhood and care services.

NDIA actuarial data provides a mixed picture of the extent to which families are happy with their child's experience of early childhood settings. The analysis of outcomes for participants from birth to school entry (June 2019) found that whilst an increasing percentage of parents feel their child is welcomed when they participate in mainstream settings, more than 30% of parents did not feel their child is welcomed. In addition, the percentage of families who wanted their child to participate more in community settings increased with an increasing percentage seeing their child's disability as the barrier to participation. Specifically:

- For participants who joined the Scheme in 2016-17, the percentage of parents/carers who say their child feels welcomed or actively included when they participate in age appropriate community, cultural or religious activities increased by 6.4% between baseline and second review, from 64.4% to 70.8%. The improvement was slightly stronger on an age-adjusted basis (8.6%).

- For participants entering in 2017-18, there was a one year improvement of 4.3% in the percentage of parents/carers who say their child feels welcomed or actively included when they participate in age appropriate community, cultural or religious activities, from 64.1% to 68.4%.

Social inclusion and interaction for children with a disability was a key concern of families:

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[48] ECEI (2016) National Guidelines for Best Practice in Early Childhood Intervention, Accessed Link to Guidelines 24 September 2020.

- For participants entering in 2016-17, proportion of parents/carers who wanted their child to be more involved in community activities increased by 14.7% between baseline and second review, from 66.0% to 80.8%. There was also a 6.4% increase in the percentage of parents/carers who say their child's disability is one of the barriers to being involved in community activities, from 81.0% at baseline to 87.5% at second review. On an age-adjusted basis, the increase was lower (5.7%).

- For participants entering in 2017-18, proportion of parents/carers who wanted their child to be more involved in community activities increased by 3.3% between baseline and first review, from 77.9% to 81.2%. There was also a 4.4% increase in the percentage of parents/carers who say their child's disability is one of the barriers to being involved in community activities, from 81.4% at baseline to 85.9% at first review.

Inclusion support, specialist equipment loans and workforce capability support are provided by the Commonwealth Government through the Department of Education, Skills and Employment to eligible mainstream Early Childhood Education and Care services. State and territory governments provide inclusion support and workforce capability support through a variety of departments for other early childhood settings.

Key issues

A significant minority of families do not feel their child is welcomed in age appropriate community settings and a majority of families would like their child to be more involved in community activities.

Some staff in early childhood education and care settings are not confident in supporting children with a diverse range of needs in ways that enable the child to fully participate and be included.

Across states and territories, the level of inclusion support and workforce capability building is variable.

Many early childhood education and care settings struggle to provide equipment that a child with additional needs may require. The NDIS provides assistive technology and equipment for participants but this is not available to non-participants and is not helpful when large pieces of equipment such as change tables are required both at home and day care. Centres eligible for Commonwealth inclusion support are assisted through an equipment loan scheme but other centres are not.

Recommendations for the National Disability Strategy

Commonwealth, State and Territory Governments to commit to consolidate and provide coordinated and additional resources to mainstream early childhood education and care settings for inclusion support and workforce capability support.

State and Territory Governments to commit funding to early childhood education and care settings to provide assistive technology and equipment for children with additional needs.

6.   Child protection

Introduction

The over representation of children and young people with disability in child protection systems is of national concern. Australian data is not easy to locate but US, UK and Irish studies place the risk of experiencing all kinds of abuse, particularly neglect, at significantly higher than that of children without disability.[49]

The overrepresentation of children with disability in child protection systems leads to disability being considered a risk factor for child safety, placing parents with disability at higher risk of having their children removed and children with disability at higher risk of being removed from their families. Little attention however is paid to strategies to mitigate that risk and support children and young people to thrive in well supported families.

The IAC paper on Participants Who are Parents documented the fear of being notified to child protection experienced by many people with disability and research demonstrating that parents with disability did not find that support is effective in meeting their needs. [50] The high rate of parents with intellectual disability involved in the child protection system suggests a significant gap in effective services for parents with intellectual disability.[51] The same can be said for parents with psychosocial disability and cognitive impairment. Research confirms that child protection practitioners focus on deficits at the expense of recognising strengths and competencies in parental capacity[52] and that services rarely meet the needs of parents with intellectual disability with parents describing the support offered as often not helpful.[53]

Research relating to parenting with an intellectual disability demonstrates that parents with intellectual disability depend on their support network; those who have little support have lower levels of wellbeing of both parents and children and poorer developmental outcomes of children.[54] Conversely adequate support is important in enhancing parenting and in keeping families together.[55] In addition, the manner in which informal social support is provided by a

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[49] Susan Flynn (2020) Theorizing disability in child protection: applying critical disability studies to the elevated risk of abuse for disabled children, Disability & Society, 35:6, 949-971, DOI: 10.1080/09687599.2019.1669433
To link to this article: https://doi.org/10.1080/09687599.2019.1669433
[50] Koolen, J., Verharen, L., van Oorsouw, Embregts (2019) "Support needs of parents with intellectual disabilities: systematic review on the perceptions of parents and professionals, *Journal of Intellectual Disabilities,* 1-25
[51] Llewellyn, McConnell & Bye (1998), Perception of service needs by parents with intellectual disability, their significant others and their service workers, *Research in Developmental Disabilities,* 19 (3) 245-260; Mildon et al 2003 *Understanding and supporting parents with learning difficulties* Melbourne Parenting Centre in Lamont & Bromfield (2009) p14
[52] NSW Dept of Community Services, 2007; Kriese, Hussein, Clifford & Ahmed 2002 in Lamont
[53] Stenfert Kroses, B BS, Hussein H, Clifford C, (2002) Social support networks and mothers with intellectual disability, *Journal of intellectual Disabilities* 14:324-240
[54] Darbyshire L V & Stenfert Kroses, B (2012) Psychological wellbeing and social support for parents with intellectual disabilities: risk factors and interventions *Journal of Policy and Practice in Intellectual Disabilities,* 9: 40-52; Llewellyn G & Hindmarsh G (2015) parents with intellectual disability in a population context, *Current Developmental Disorders reports,* 2: 119-126 reported in Koolen et al (2019)
[55] Aunos M & Pacheco L (2013) Changing perspectives: workers' perceptions of interagency collaboration with parents with intellectual disability. *Parents with Disabilities in Child Welfare* 7: 658-674; Booth T and Booth W (1999) Parents Together: Action research and advocacy support for parents with learning difficulties *Health & Social Care in the community* 7: 464-474; Llewellyn G (1997) Parents with intellectual disability learning to parent: the role of experience and informal learning, *International Journal of Disability, Development and Education,* 44:243-261 reported in Koolen et al (2019

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diverse range of supporters shapes the ways in which mothers understand, learn about and carry out mothering[56] [57] [58].

Research demonstrates that to improve service delivery for parents with intellectual disability, interventions should be family centred, focused on family and parental strengths[59] and help at home with practical tasks such as transport.[60] Interventions should focus on specific skill development [61] through performance based rather than knowledge-based programs.[62]

Key issues

Where disability is identified as a risk factor in relation to child protection, parents with disability experience an increased risk of being notified and having their child removed. Whilst reliable data is not available, anecdotal evidence led advocacy organisation Speak Out Tasmania to use an ILC grant to facilitate conversations between mainstream services and parents with intellectual disability to improve the responsiveness of support. They used the slogan *Support Before Report* to emphasise the reorientation required.

Little attention was paid to disability in the National Framework for Protecting Australia's Children 2009-2020.

Universal parenting programs are the responsibility of community services, family support and health sectors and most parenting classes are not adjusted to enable participants with cognitive or psychosocial disability to gain core competences. NDIA support in developing parenting skills is only available when the mainstream option has failed, often too late for a pregnant woman with disability.

Parents with disability are notified to child protection agencies often without their knowledge. This deprives them of the opportunity to secure additional support that would assist them in parenting.

Recommendations for the National Disability Strategy

The National Framework for Protecting Australia's Children 2009-2020 is to be renegotiated shortly. The first plan under the next strategy should focus on children with disability with strategies to understand the issues clearly and strengthen the whole of government response.

Child protection services must develop risk assessment tools that appropriately guide child protection workers to view parents in the context of supports.

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[56] Llewellyn, G., Mayes, R., & McConnell, D., (2008) Towards acceptance and inclusion of people with intellectual disability as parents, *Journal of Applied Research in Intellectual Disabilities,* 21, 293-295

[57] Mayes, R., Llewellyn, G., & McConnell, D., (2008), Active negotiations: mothers with intellectual disabilities creating support networks, *Journal of Applied Research in Intellectual Disabilities, 21(4), 341-350*

[58] Llewellyn, G., McConnell, D., & Bye, R., (1998) Perception of service needs by parents with intellectual disability, their significant others and service workers, Research in Developmental Disabilities 19(3):245-26

[59] NSW Department of Community Services (2007), *Parental intellectual disability/Learning difficulties vulnerability,* Brighter Futures Practice Resource; Wade, C.,Mildon, R. & Matthews, J (2007) Service delivery to parents with an intellectual disability: family centred or professional centred? *Journal of Applied research in Intellectual Disabilities, 20:87-98*

[60] Wade, (2007) Wade, C.,Mildon, R. & Matthews, J (2007) Service delivery to parents with an intellectual disability: family centred or professional centred? *Journal of Applied research in Intellectual Disabilities*, 20:87

[61] Wade, C (2007) ibid;

[62] McGaw, S, & Newman, T (2005) *What works for parents with learning difficulties* (2nd edition), Ilford: Barnados, reported in Lamont, A & Bloomfield, L., (2009); Mildon, R., Matthews, J., & Gavidia-Payne (2003) *Understanding and supporting parents with learning difficulties*, Melbourne: Victorian Parenting Centre

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When child protection services receive a notification of an NDIS participant, the child protection agency should refer the parent back to the NDIS for an urgent plan review to meet expectations of the child protection agency.

Mainstream community, family support and health providers responsible for parenting programs must to be required to make reasonable adjustments to enable parents who have a disability to gain the core competencies required.

7.   Families and carers

Introduction

The support provided by families and carers are critical to the sustainability of the NDIS.

The NDIS intended that families and carers would be supported via reasonable and necessary support that enabled participants to achieve their goals. Most families and carers are pleased for the increased opportunities for their family member with disability but feel exhausted and overlooked by the NDIS. Actuarial data indicates that whilst health and wellbeing of participants has improved under the NDIS, health and wellbeing of families and carers has deteriorated.

Analysis of future demand and supply of informal carers by Deloitte Access Economics[63] suggests a widening gap between demand and supply that will have significant implications for the NDIS and all governments. The report's recommendations to reduce the deficit in caring include greater flexibility in working arrangements, strategies to alleviate the impact of caring including carer respite services and improving the flexibility of care options.

In the UK, the policy shift to individual budgets for people with disability has seen the concurrent introduction of a policy framework for assessing carers' needs independently of the needs of the persons for whom they care. Sweden and the Netherlands have a form of carer assessment or brokerage resembling that of the UK. In the US, research points to the proliferation of consumer-directed family support programs that assess the needs of all members of the family at once, suggesting positive outcomes for both participants and carers.[64]

The Australian Government introduced a new model of carer support services (Integrated Carer Support Services (ICSS)) in 2018 to replace those it used to fund under the previous system. ICSS recognises carers in own right but the resources allocated do not restore the funding transferred to the NDIS with a limited number of ICSS packages of $3,000 for respite. Families continue to be forced into crisis

Carers Australia reviewed evidence of the impact of COVID 19 on carers in Australia and comparable jurisdictions and found:

- adverse impacts on the mental health and stress levels of carers and the people they cared for, and the increased isolation in lockdown;

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[63] Deloitte Access Economics *The value of informal care in 2020*, Carers Australia May 2020.
[64] Productivity Commission 2011, *Disability Care and Support,* Report No. 54, Canberra

- reduced service access to respite opportunities including the use of formal services and informal opportunities to take a break from the caring role; and
- considerable challenges maintaining employment responsibilities while caring for someone at home including children with additional needs who were unable to attend school and were not well catered for in a digital environment.

Key issues

Carer resources have been significantly depleted with introduction of NDIS - '*direct funding for support services to assist carers with their own needs has been declining over a number of years with the introduction of the NDIS and national aged care reform which have seen the transfer of some funds and programs from carer support to the support of those they care for*'.[65]

The health and wellbeing of families and carers has deteriorated. The June 2020 NDIS Quarterly Report [66] demonstrates that the NDIS has not yet had a significant impact for many families and carers. Reports of the health of families and carers 'not being good, very good or excellent' and reports of families and carers being unable to work as much as they want, provide a picture that at least one third of families and carers are not well supported. The issue comes into sharp focus with the Quarterly Report data that more than 85% of those who report being unable to work as much as they want cite the situation of their family member with disability as a barrier to greater workforce participation.

The Australian Government new model of carer support services does not replace let alone increase the resources devoted to carer support prior to the NDIS.

The NDIS relies on support by informal carers but families and carers indicate that planners and LAC partners do not understand what is required to sustain their caring role.

States and territory governments have variable track record to provision of carer supports with some states providing no support in the post NDIS environment.

Recommendations for the National Disability Strategy

Develop and resource a new National Carer Strategy to:

- increase resources to family and carer support to at least pre NDIS days; and
- provide a clear seamless pathway to support for carers in their own right

State and Territory governments to increase resources to family and carer support programs.

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[65] Q&A regarding announcement of the National Approach to Carer Support Services, March 2018
[66] at p115

8.   Education

Introduction

The Australian Civil Society Report to the UN on the rights of peoples with disabilities (the Shadow Report)[67] documents the very disappointing picture experienced by students with disability in Australian schools with evidence of routine discrimination, lack of supports, inadequately trained teachers, a lack of expertise and an entrenched systemic culture of low expectations. [68] AIHW data indicates that approximately 3 in 4 students with disability experience difficulties at school, predominately due to fitting in socially, communication difficulties, and learning difficulties.[69] The lack of national data on suspension, restraint and seclusion of students with disability in the context of increases in segregation over the past decade demonstrates the need for significant action on education in the National Disability Strategy.

The Coalition for Inclusive Education outlines the transformation needed to ensure Australian education systems comply with the UNCRPD so that all children and young people are welcomed and educated in the regular class of mainstream schools with adequate support. Key levers for change are seen to lie in legislative/policy change, more effective monitoring and accountability, parent education and support, teacher education, transforming school cultures for inclusion and giving students' agency and voice. The fact that a 2019 survey[70] found that 15.1% of students use NDIS funding to assist them to access and participate in education[71] also indicates that nationally, education systems are not providing adequate support for inclusion.

The missing voice for students with disability has been evident during the COVID 19 pandemic, where students with disability faced significant reductions in the provision of the usual supports from education facilities, most notably supervision, social supports and individual support workers. While all Australian children and young people faced uncertainties and disruptions *children and young people with disability arguably faced an even more difficult time and greater impact to their education, not because of their impairments, but as a result of our underlying social structures and systems.*[72]

Key issues

The lack of a national legislative or policy framework for inclusive education leaves students with disability battling at the school gate one student at a time.

Children and young people with disability engaged in education were not well supported during the COVID-19 pandemic. A recent study by CYDA reported that schools had indicated they

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[67] Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities (2019) in response to the List of issues prior to the submission of the combined second and third periodic reports of Australia [CRPD/C/AUS/QPR/2-3]. Compiled by the Australian Civil Society CRPD Shadow Report Working Group, July 2019.

[68] Shadow report p35

[69] 203 Australian Institute of Health and Welfare (2017) Disability in Australia: changes over time in inclusion and participation in education. AIHW, Canberra.

[70] Children and Young People with Disability (2019), Time for change: the state of play for inclusion of students with disability, Results from the 2019 CYDA National Education Survey, p11

[71] Children and Young People with Disability (2019), op cit, p11

[72] Dickson, H, Smith, C, Yates, S, Bertuol, M, (2020) Not even remotely fair: experiences of students with disability during CCOVID-19. Report prepared for Children and Young People with Disability Australia (CYDA) Melbourne

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were unable to provide support for students in their education or dramatically reduced support, responsibility for education shifted from teachers and schools onto parents with parents required to translate learning materials into a format that was useful for their children and Individual Education Plans not working the way they should. In addition, the NDIS was slow and inconsistent in its response to the changed needs of participant students.[73]

The study found however that student wellbeing was enhanced when schools made sure that students with disability were socially connected to their peers and the school and where there was planned and intentional support.

Recommendations for the National Disability Strategy

Develop a National Action Plan for Inclusive Education that includes a legislative and policy framework that fully complies with Article 24 and CRPD.

Develop and resource a national plan for support for children and young people in education in the pandemic.

Clarify and resource the roles and responsibilities of the NDIS and mainstream education in support for children and young people being schooled at home in the pandemic.

9.   Employment

Introduction

Australia ranks 21st out of 29 Organisation for Economic Co-operation and Development (OECD) countries in employment rates for people with a disability. Australia ranks 27th out of 27 OECD countries when it comes to the relative poverty risk for people with a disability.[74]

The 2016 *Willing to Work Report* [75] documents challenges in services and systems that prevent people with disability getting into work. These challenges include that many employers have no understanding of pathways to support employees, that the rate of employees transitioning out of supported employment into open employment is unacceptably low (less than 1%) and that people with disability do not feel that DES staff understand their desire for a career.

The DES policy of excluding people with disability deemed unable to work a minimum of 8 hours per week may have contributed to our low standing compared to other OECD countries because it removed a whole class of people who successfully secured and retained jobs in open employment in the 1970s, from the possibility of employment. This DES policy has certainly contributed to a loss of knowledge, skills and experience in helping people with significant disability to secure and maintain open employment.[76]

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[73] Dickson, H, Smith, C, Yates, S, Bertuol, M, (2020), p25

[74] Reported in Australian Human Rights Commission, 2016, *Willing to Work*, Report of the **National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability.**

[75] Australian Human Rights Commission, 2006 op cit.

[76] Research by Gold, Bellamy, Horner, Inman, Moss, Wehman and Brown, reported in Cain, P, The knowledge of assisting people with intellectual disability to participate in employment *Interaction,* v18, no 3 2005

The majority of NDIS participants in employment do not however earn a living wage with only 41% of participants 15-24 years in a paid job in open employment at full award wages and a further 14% in open employment at less than full award wages. The corresponding percentages for the 25-64 cohort are lower at 33% and 10%.[77]

Many people with disability are frustrated about relying on welfare benefits, such as the Disability Support Pension (DSP), when they have the ability and readiness to work.[78] For many however, the motivation to seek open employment is impeded by their perceived fear of financial insecurity associated with loss of the DSP including the uncertainty of unskilled employment and the mutual obligation requirements related to the Newstart Allowance. Section 10 of this submission outlines disincentives to workforce participation related to the DSP. Safety net provisions for income security would give confidence to many NDIS participants to extend their aspirations to open employment.

Key issues

Disability employment programs are poorly designed

Disability employment programs are poorly designed inhibiting people with disability from getting effective support to find and maintain a job. Challenges lie in the early streaming of school leavers, the current program structures and the variable effectiveness of providers.

The base line of the current employment landscape for people with disability is a two-tiered system: Disability Employment Services (DES) for people deemed able to work a minimum of 8 hours per week and a supported employment system (ADEs) for other people with an employment goal. ADEs and some DES providers have transitioned into the NDIS as registered providers of employment supports.

DES has a history of securing employment outcomes for people with significant disability in the 1980s using customised employment. Many stakeholders now argue that the 21st century DES needs a major redesign if it is to be fit for purpose for NDIS participants. Under the DES risk adjusted funding and performance framework, job seekers who are more challenging to place and maintain in work are not prioritised and this is reflected in the fact that only 7% of DES customers have an intellectual disability.[79] In addition, many commentators note that practices such as incentive payments to employers make it unprofitable to support participants beyond 26 weeks and in consequence many participants lose their jobs when the DES wage subsidy cuts out. People with intellectual disability and ASD seem to be especially impacted.

A person-centred system of employment support is necessary. This would involve:

- automatic eligibility for DES[80] so that NDIS participants of working age can use mainstream employment services charged with helping people with disability to find and retain work.

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[77] NDIS Actuarial data

[78] (Commonwealth Department of Social Services,2011; National People with Disabilities Carers Council [NPDCC], 2009)

[79] National Disability Services, (2018) Response to discussion paper *Ensuring a strong future for supported employment*

[80] To make automatic eligibility for DES meaningful would require:
- removal of current Employment Services Assessment and Job Capacity Assessment that determine income support entitlement
- removal of min 8 hours work requirement
- new categories of risk adjusted funding that would enable job development including customised employment

- reasonable and necessary support in the domain of employment to enable the participant to choose where they want to work, who supports them at work and how.

These two elements disrupt the current employment landscape by:

- removing the current program structures that define supported employment as a place of employment for a targeted group of people[81]
- linking support for employment to the participant rather than the provider
- identifying the role of mainstream agencies (DES) as providing the support necessary for the participant to obtain work with the employer to provide reasonable adjustment for the job
- deriving the function of NDIS reasonable and necessary support as *supports for participants over and above the supports available under reasonable adjustment by the employer or available under the DES model regardless of employment setting.*[82]

Together, these proposals transform supported employment into support FOR employment enabling the participant to apply that support in employment of their choosing.

Eligibility for DES must also facilitate access to other mainstream employment services such as New Enterprise Incentive Scheme (NEIS), Job Access, Job in Jeopardy and Youth Employment Supports, requiring appropriate adjustment to program guidelines to ensure meaningful access by all NDIS participants.

Employment providers perform poorly

A significant proportion of participants of working age use ADEs, many paying at a rate designed to retain the DSP rather than reflect productivity. ADEs must change to support participants on a pathway to growth and development, further training and the opportunity to move to open employment or they must transition to social firms.

Most NDIS participants use registered disability employment and disability support providers to help them find, customise and maintain a job. NDIA actuarial analysis[83] documents the wide range of performance amongst registered providers with a small number of employment providers with 'exceptional' results and the majority performing poorly.

Strategies that will enhance performance of employment providers include:

- mechanisms to share good practice

- appropriate adjustment of DES performance framework recognising the additional time and work required
- new requirement that customised employment is a core skill of DES providers
- removal of restrictions related to working with people who are already in work to support the aspiration that participants have a career, not just a job is to be met.

[81] Current programs guidance is derived from Section 8 of the *Disability Services Act 1986* that defines supported employment as services for a) people who are unlikely to attain competitive employment and b) people who need substantial ongoing support to obtain and retain employment

[82] NDIS, "Supporting NDIS participants' employment goals" p4 (undated discussion paper distributed by to the NDIS Participant Employment Taskforce

[83] Regression analysis models are used to determine the number of participants expected to be in paid employment at review based on the characteristics of the participants supported by the provider

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- scoping the core competencies, training, practice frameworks and systemic requirements that would enable a customised approach to become expected practice of DES, and NDIS registered providers.
- the NDIS sending the strongest possible signals to the market as to the desired policy direction of supporting participants on a pathway to of growth and development, further training and the opportunity to move to open employment or the transition of the ADE to a social firm via: pricing incentives, supporting participants to become more informed and the publication of good practice guides including guides to transition.

Targeted employment creation required

Targeted employment creation is required to make any significant difference to the employment participation of people with disability. Incentives to encourage the creation of employment opportunities targeted at people with disability include:

- Performance requirements on CEOs
- Social procurement processes
- Employment registers
- Affirmative action under the National Disability Strategy
- Reduction in red tape associated with taking on an employee through DES
- Annual PM award
- Tax incentives for employing people with disability
- Tax incentives for social firms
- Clear and trusted advice and support.

Disincentive to employment arising from the DSP are discussed in the next section.

Recommendations for the National Disability Strategy

Develop and implement a person-centred system of employment support, designed around the individual. This includes automatic eligibility for a DES (with adjustments identified in the submission) so that NDIS participants of working age can use mainstream employment services charged with helping people with disability to find and retain work.

Enhance the effectiveness of employment providers.

Review the disincentives of the income support system and maximise workforce participation of DSP recipients.

Commonwealth, State and Territory Governments to implement incentives that encourage the creation of employment opportunities targeted at people with disability.

10. Income support

Introduction

Since 2018, the NDIA has been linking its participant data with Centrelink data, which has allowed NDIS participant usage of the DSP to be examined. The linked data provides a view

of each participant's DSP status throughout their time in the Scheme, which when combined with the data available through the Outcomes Framework survey data, has allowed the NDIA to analyse differences in employment outcomes between participants receiving the DSP (DSP participants) and participants not receiving the DSP (non-DSP participants), and to identify opportunities to potentially improve employment outcomes across the NDIS.

Employment has a considerable positive impact on the overall wellbeing of people with disability. Not only does participation in paid employment increase an individual's level of financial independence, it can also lead to a greater sense of identity and social inclusion. This in turn may lead to positive physical and mental health impacts for people with a disability who engage in the workforce.

Whilst many people with disability are frustrated about relying on the DSP when they have the ability and readiness to work, for many the motivation to seek open employment is impeded by their perceived fear of financial insecurity associated with loss of the DSP including the uncertainty of unskilled employment and the mutual obligation requirements related to the Newstart Allowance. Safety net provisions for income security would give confidence to many NDIS participants to extend their aspirations to open employment.

Key issues

There are three elements of the DSP that are more likely to be a disincentive to DSP participants maximising their workforce participation.

1. Participants are required to demonstrate a 'continuing inability to work for at least 15 hours a week' in order to qualify for the DSP. This requirement combined with the possibility of eligibility reviews, may create the perception that working more than 15 hours will lead to a review and cancellation of payments.

2. DSP payments reduce by 50c for each dollar earned over $174. The reduction in the DSP benefit where income exceeds $174 per fortnight creates a disincentive to work more hours per week compared to non-DSP participants.

3. DSP payments are suspended for recipients who work more than 30 hours a week resulting in a step down in total net income.[84] There is therefore a financial disincentive for DSP participants to work more than 30 hours per week.[85]

To test the strength of these features as barriers to maximising workforce participation, the Scheme Actuary built a series of models that evaluate differences in employment outcomes between DSP participants and non-DSP participants, whilst also allowing for differences in employment incomes between different types of participants.

The analysis found that participants not receiving the DSP are more likely to want and find paid work, and work more hours at higher wages than participants receiving the DSP.

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[84] Excluding participants earning a wage of $34/hour or more, as the additional employment income per hour more than offsets the loss of DSP income

[85] Participants employed under an Australian Disability Enterprise agreement or Supported Wage System are exempt from this rule

Comparison of employment outcomes shows that, in general, non-DSP participants are more likely to have positive employment outcomes compared to DSP participants. However, the mix of these participants in terms of their age, primary disability type, level of function and remoteness area differs from DSP participants. After allowing for the difference in mix, the analysis showed that non-DSP participants are:

- 1.2x more likely to have or seek paid work

- 1.3x more likely to find paid work

- Equally as likely to retain paid work once employed

- 1.6x more likely to be employed at full wages

- 1.5x more likely to work more than 30 hours per week

Scenario testing led to the conclusion that removing some of the DSP-related disincentives to employment is expected to result in a higher net revenue both for NDIS participants and government and this will increase as more participants join the NDIS.

Scenario	Estimated impact over the years to 30 June 2020	
	NDIS participants[86]	Government with respect to NDIS participants[87]
1. Remove the 30-working hour per week cut-off for receiving pension payments	$9m	$19m
2. Remove the need to reapply for the DSP after having exceeded the 30-working hour per week cut-off for more than 2 years	$17m	$52m
3. Reduce the pension penalty for those earning more than $174 per fortnight, from 50 cents to 25 cents	$58m[88]	-$36m

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[86] Change in employment income (net of taxation) and DSP benefits received. A positive number indicates more disposable income for participants (approximately 159k NDIS participants are considered in this analysis).
[87] Change in taxation revenue and expenditure on DSP benefits. A positive number indicates a higher net revenue for the government, i.e. additional taxation revenue exceeds the increase in DSP expenditure.
[88] Estimates are based on a scenario that assumes a 5% uplift in workforce participation driven by the reduced disincentive associated with a reduction in the penalty rate

Source: NDIA Disability Support Pension – Executive Summary.

Recommendations for the National Disability Strategy

Department of Social Services to review the disincentives of the income support system (Newstart, DSP) and maximise workforce participation of people with disability.

DSS to extend safety net provisions for income security to NDIS participants to extend their aspirations to open employment. Strategies include:

- reviewing DSP taper rates;

- publicise information about return to DSP for recipients who drop working hours or loose employment, and provisions for not having to reapply to the DSP; and

- secure automatic eligibility to a Health Care Card for NDIS participants (given Mobility Allowance is now part of the NDIS).

11.   Housing

Introduction

The national crisis in affordable housing makes it very difficult for people with disability to find housing they can afford. These difficulties result from challenges in the private rental market, their lack of priority in social housing, the lack of requirements on developers that would foster more affordable housing and the lack of financing options that could encourage investors and families to contribute to the provision of affordable housing.

For people with challenges related to mobility, the constraints are even more significant as a result of the lack of mandatory minimum standards related to accessibility and a lack of action by the housing industry. In 2011, COAG agreed to an aspirational target of all new housing being accessible by 2020. Even though in some jurisdictions, accessible and affordable housing is being built in new residential developments due to inclusionary zoning,[89] the Civil Society Shadow Report to the UN in 2019[90] estimates that only 5% of new housing construction will have met the standards by 2020[91] and that regulatory intervention through the National Construction Code is required to achieve change.[92]

The Australian Building Codes Board has been consulting on a Regulation Impact Statement (RIS) for the inclusion of minimum accessibility standards for all housing in the National Construction Code. The RIS considers five options for setting minimum accessibility standards

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[89] Melbourne Disability Institute& Summer Foundation (2020), *Accessible housing: the way forward,* Response to the Australian Building Codes Board Consultation RIS, p20

[90] Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities (2019) in response to the List of issues prior to the submission of the combined second and third periodic reports of Australia [CRPD/C/AUS/QPR/2-3]. Compiled by the Australian Civil Society CRPD Shadow Report Working Group, July 2019. P31

[91] This is due to the voluntary nature of the target and the number of compliant houses currently being produced. See: Senate Standing Committee on Community Affairs (29 November 2017) Delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities. Commonwealth of Australia.

[92] Australian Government (2016) National Disability Strategy 2010-2020: Progress Report to COAG.

for housing based on a social cost-benefit analysis. Following the current consultation, a Final RIS will be sent Commonwealth, State and Territory governments Building Ministers for consideration and decision.

Impacts of lack of affordable, accessible housing

2020 research[93] prepared to measure quantitative and qualitative impacts of living in accessible and inaccessible housing demonstrated that a lack of accessible housing: reduced people's ability to work or reduced their productivity; led to additional NDIS spending and reliance on informal supports; and led to adverse effects on mental health.[94]

In summary, the lack of affordable, accessible housing means that:

People with disability continue to enter and remain in inappropriate housing

People with disability are forced to live in inappropriate housing including residential aged care for want of alternatives. 2018 statistics indicated with almost 6,000 people under 65 live in residential aged care facilities across Australia of whom 188 were under 45 and 30 were under 35 years.[95] Others remain living with families whose capacity to care is diminishing. In both these situations, people fail to gain skills or lose skills for want of opportunity to become more independent. Some become frustrated and exhibit behaviours of concern and some remain living in shared supported accommodation when they are able to live more independently.

There is a growth in demand for traditional shared living options

Traditional shared living options include group homes that are costly, do not produce positive outcomes for their residents and are documented places of abuse and neglect.[96]

Providers of accommodation support have understood the impact of a lack of affordable housing and purchase houses in which they group people who could be supported more independently in the community.

Families and carers remain out of the workforce

Families and carers remain out of the workforce or work at reduced levels as a result of caring responsibilities.[97] Many are tired and alienated and lose the capacity to support the transition of their family member from family home to their own home.

The cost of support increases

When people with disability live in the constant presence of staff, there is a natural tendency toward dependence. The impact is that people lose competence and confidence to use their skills and engage in the community in ways that build independence.

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[93] Melbourne Disability Institute op cit.
[94] Ibid p5
[95] DSS Young people in residential aged care action plan. Accessed Link to Paper
[96] Bigby, C., Bould, E., & Beadle Brown, J., (2015), Optimising outcomes for people with intellectual disability in supported living arrangements, p12
[97] NDIA actuarial data indicates that whilst health and wellbeing of participants has improved under the NDIS, health and wellbeing of families and carers has deteriorated.

The cost of transport increases

People with disability are forced to use taxis because public transport is not accessible and housing is not located close to public transport that is accessible.

People miss out on opportunities for employment

People with disability have become dependent and are not as nimble as they may otherwise be, resulting in them missing out on employment opportunities.

Challenges in locating suitable housing

There is no efficient and effective platform that enables people with disability who require accessible housing to locate suitable properties as there is no central data repository that is reliable and valid for all Australian states and territories. There has been some increase in accessible stock in new residential developments (as a result of inclusionary zoning) and because many dwellings have been modified substantially for occupants with mobility limitations, often funded by the NDIS, health, local government and motor accident schemes. However, once the occupant with disability moves on, these accessible dwellings are sold and leased to the general population.

Melbourne Disability Institute[98] outlined collaboration that could lead to an effective register of accessible dwellings, including collaboration between the Real Estate Institute of Australia, Livable Housing Australia, NDIS, Summer Foundation, state work and accident compensation schemes, large developers, access consultants and State governments. The Melbourne Disability Institute recommends initial steps of collaboration to develop a register with a pilot in a local government area.

Key issues

Many people with disability are not prioritised for social housing in the context of a national shortage of affordable housing.

Many people with disability require accessible housing that incorporates design features that are not widely available. The RIS for the inclusion of minimum accessibility standards for all housing in the National Construction Code provides a unique opportunity for the NDS to increase the supply.

There is no reliable way for people requiring accessible housing to identify suitable properties.

Recommendations for the National Disability Strategy

There must be a commitment to significant growth in affordable, accessible housing targeted to people with disability under the National Disability Strategy. This includes ensure all social housing is built to Livable Housing Design Gold Standard (LHDG) and a significant increase supply of accessible housing

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[98] Melbourne Disability Institute & Summer Foundation (2020), *Accessible housing: the way forward,* Response to the Australian Building Codes Board Consultation RIS

In order to increase the supply of accessible housing, the National Disability Strategy must require the inclusion of minimum accessibility standards for all housing in the National Construction Code recommending Governments and the Australian Building Code Board:

- Adjust the National Construction Code to set minimum mandatory accessibility standards, broadly reflecting the Livable Housing Design Gold Standard (LHDG) for all new Class 1a and Class 2 buildings[99]

- Explore the potential for a subsidy program to encourage availability of accessible rental properties[100] to be implemented over the next 10-15 years, while the stock of accessible housing grows.

- Ensure the new accessibility housing standards are based on the current LHDG and not the diluted version, as described in the draft of proposed changes to the National Construction Code, and

- Initiate a pilot to make better use of the existing accessible housing stock using the existing infrastructure provided by the Housing Hub and/or Nest matching platforms.

12.   Justice

Introduction

NSW Council for Intellectual Disability describes many of challenges faced by people with cognitive impairment in touch with the criminal justice system including:

- Lack of consistent recognition of people as having intellectual disability and therefore needing reasonable accommodation in communication and other matters.

- Communication challenges between person with intellectual disability and justice system personnel.

- Difficulty understanding and exercising rights, for example the right to silence in a police interview.

- Challenges for victims of crime in being believed by police and being seen as a competent witness.

- Dependency on legal aid lawyers who are time poor due to very high caseloads.

- Limited access to bail, diversionary orders, non-custodial sentencing options and parole due to limited availability of appropriate disability support and other human services including stable and appropriately supported accommodation.

- Within custodial environments, being vulnerable to abuse and developing entrenched propensity to reoffend due to the negative influences and role models in custodial environments.

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[99] Op cit, Option 2 of the RIS
[100] Op cit, Option 5 of the RIS

- On release, challenges in moving from the highly structured environment of custody to an unstructured environment in the community.

Some states and territories had taken positive steps to address these challenge but the introduction of the NDIS destabilised many of state-based initiatives leaving people with cognitive impairment without support. Challenges include increased difficulty in getting disability support services to underpin a diversionary order from the court, increased difficulty in obtaining disability support to avoid a person being unnecessarily remanded in custody, difficulties developing NDIS plans for people in prison and some people with complex needs not been taken up by services.[101]

Both the NDIS and the NSW Government for example, took steps to respond to people with disability interacting with or at risk of engagement with the justice. The NDIA introduced the complex needs pathway, specialist planners and Justice Liaison Officers. The NSW Government implemented three time-limited programs as part of transitional arrangements: the Integrated Services Response,[102] the Community Safety Fund[103] and the Cognitive Impairment Diversionary Program (CIDP). [104] All have now ceased.

As of mid 2020, the NSW Department of Justice is reported to be working with key stakeholders to replace the CIDP with a scalable model for people with cognitive impairment in the criminal justice system.

Key issues

Some people with cognitive impairment are poorly supported and are picked up by the criminal justice system for want of diversion that can be activated in the presence of effective, skilled support.

The NDIS takes a narrower view of its role than previous state and territory governments and under the interface principles, state justice departments are required to provide support for which they have little preparation or motivation.

If people with cognitive impairment at risk of engagement with the criminal justice system are to be successfully supported:

- mainstream agencies must provide:

  o early intervention in schools and other services where children and young people show signs of becoming offenders;

  o independent support in police interviews and criminal courts so that people with cognitive impairment are able to understand and exercise their rights;

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[101] NSW CID 2017 Roundtable on Meeting Complex Behaviour Support Needs in the NDIS Accessed https://cid.org.au/our-stories/a-pathway-through-complexity/ 15 September 2020

[102] A project based in NSW Health that coordinated a small number of people with complex needs across the NDIS and mainstream services

[103] A transition support, established to maintain case coordination and clinical team residue of the Community Justice Program where the NDIS had been inadequate for an individual

[104] Provided screening and assessment as to whether a defendant had a cognitive impairment, supporting access to the NDIS and providing a diversion plan to support dismissal of charges.

- - court diversion systems for young people and adults with cognitive impairment; and

  - enhanced practice in skill development correctional systems in working with offenders with intellectual disability.

- The NDIS must ensure the provision of:

  - outreach and engagement with potential and actual offenders with cognitive impairment;

  - skills development across the disability support agencies in working with offenders with cognitive impairment; and

  - specialist workers, skilled in working with offenders with cognitive impairment, both directly with people with complex needs and as a resource to other support providers.

Recommendations for the National Disability Strategy

National, state and territory governments need to resolve issues of interface responsibilities between the NDIS and state justice and other agencies.

State and territory governments must develop and implement programs such as:

- Justice advocacy services: providing support to people with cognitive impairment in police interviews and criminal courts.

- Cognitive Impairment Diversion Program: providing short-term intensive casework into appropriate disability and other support and thereby enabling diversion from the criminal courts.

- The case coordination and clinical teamwork of the former Community Justice Program: providing short-term specialist assessment and case coordination to facilitate access to the NDIS and other necessary services for people with serious histories of offending.

- The State-wide Disability Service and additional support units in corrective services: aimed at ensuring the safety and meeting the support and program needs of prisoners with disability and people supervised by community corrections.

- Psychological and other services in Juvenile Justice NSW to meet the needs of young offenders with intellectual disability.

b. The implementation of the above should be driven and co-designed by people with disability, their families and carers.

State and territory governments must also ensure that its mental health and alcohol and other drug services are accessible and appropriate for alleged offenders with intellectual disability.

13.   Domestic and family violence

Introduction

Services that support people with disability often have very limited capacity to respond to risks of domestic and family violence, while services focused on violence prevention have little background or resourcing for identifying and addressing disability support needs. This may result in risks of either unmet need or of inappropriate response, including women with disability who are victims of violence returning to the place of victimisation, invariably 'their home', and/or interventions by statutory child protection services, due to lack of available alternative support.[105]

There have been inquiries in relation to domestic and family violence at the Commonwealth and State level and the Australian Government has recognised the need to foster innovative and collaborative service delivery.[106] Much more is required so that wherever they live, women with disability can be supported to escape domestic and family violence and build good lives.

Key issues

Women with disability are often unaware of their rights and unable to access support in a timely way because information about sexual and safety rights is often not provided to people with disability and generic community information campaigns are not accessible to or targeted at women with disability. In addition, some women with disability have never accessed disability supports, having been denied access by partners and families as a form of control or even as assumed protective measures.

Some states and territories have taken strong action in response to Commissions of Inquiry but practice across Australia varies significantly. The Australian Civil Society Report to the UN on the rights of peoples with disabilities (the Shadow Report)[107] documents the lack of expertise and structural barriers within domestic violence, sexual assault and women's crisis services that prevent appropriate responses to support women with disability. The Shadow Report identifies some of the barriers as challenges with data collection, the national service response through its 1800RESPECT service and the largely project funded and one-off initiatives funded in the National Plan.[108]

In most states and territories, there is a presumption that the victim survivor with disability must leave the property[109] but the shortage of responsive crisis accommodation makes this a challenge for many women with disability. This is especially the case where a women requires physical access and equipment, when she has adolescent sons with disability or when accessing the service requires her to move away from her local area to be safe. In addition,

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[105] Robinson, S., Valentine, k., Newton, B. J., Smyth, C., & Parmenter, N. (2020). Violence prevention and early intervention for mothers and children with disability: Building promising practice (Research report, 16/2020). Sydney: ANROWS.

[106] Reporting on $2.058m in funding to UN in Convention on the rights of Persons with Disabilities, Combined second and third periodic reports submitted by Australia under article 35 of the Convention, Due 2018 Issue 6 pt. 65, p9

[107] Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities (2019) in response to the List of issues prior to the submission of the combined second and third periodic reports of Australia [CRPD/C/AUS/QPR/2-3]. Compiled by the Australian Civil Society CRPD Shadow Report Working Group, July 2019.

[108] Op cit, p6

[109] In Victoria the assumption is that the perpetrator will leave the property, however, there are occasions where if the victim stays there will be a fear factor that he will return

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crisis accommodation services often will not allow people who are not service recipients or staff and/or who are men onsite, and this may mean some women are unable to use their pre-existing disability supports. Attitudes that 'it is just too hard' can also hinder women with disability accessing the crisis support they need.

Recommendations for the National Disability Strategy

Domestic and Family Violence sector

- Ensure that the *National Plan to Reduce Violence Against Women and their Children* is inclusive of all forms of gender-based violence, regardless of the setting and the perpetrators of such violence.
- Ensure that the outcomes and strategies related to women with disability in the National Plan to Reduce Violence Against Women and their Children align to those in the Strategy, and that women with disability are consulted as part of the process.
- Ensure gender-based violence services:
    - are inclusive of and responsive to women and girls with disability and women with children with disability; and
    - build inclusive practice focusing on barriers to support rather than impairment.[110]
- Expand the provision of Family Violence Flexible Support Packages for women with disability to all states and territories.
- Challenge the presumption that the victim survivor with disability must leave the property.
- Remove barriers to crisis supported accommodation for women with disability and women with children with disability including ensure:
    - accommodation services include disability accessible units; and
    - alternate accommodation is available for women with adolescent sons with disability.
- Ensure disability training for all domestic and family violence workers is undertaken by people with disability who understand disability and family/domestic violence.
- Provide information in accessible languages, including easy English, audio and video.
- Adopt a consistent and comprehensive approach to data collection on people with disability escaping domestic and family violence.

Department of Social Services

- Resource and support DPOs to develop and implement initiatives to address violence against women with disability.
- Adequately support organisations and networks of women with disability to engage in all initiatives to promote gender equality.

Collaboration

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[110] Robinson, S., Valentine, k., Newton, B. J., Smyth, C., & Parmenter, N. (2020). Violence prevention and early intervention for mothers and children with disability: Building promising practice (Research report, 16/2020). Sydney: ANROWS

Establish mechanisms to fund collaborative programs that promote cross sector learning and joint planning and provision of support.

- Areas for joint learning include the nature of violence against women with disabilities, ableism, barriers to safety faced by women with disabilities, sexual and safety rights for women with disability
- Joint planning and provision of support including collaboration in provision of flexible support especially where short-term accommodation is required.

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