Improving outcomes for people with disability under the National Disability Strategy and the NDIS

Submission to the Department of Social Services

December 2020

Table of Contents

Introduction

The Independent Advisory Council (Council) to the NDIS developed a comprehensive submission in relation to the National Disability Strategy (NDS), outlining commitments required to close the gap between people with and without disability. Council expressed pleasure at the government commitment to improved accountability in this Strategy, and looked forward to the establishment of rigorous systems to collect, disaggregate, disseminate and report on data to measure progress.

The draft Outcomes Frameworks is an important first step in monitoring achievements under the Strategy, and when implemented will highlight progress under this and future strategies.

This submission provides general feedback on the proposed outcome measures. Drawing on Council's submission on the NDS, it also outlines background information that should be used to shape outcome measures, source barriers and locate responsibility as well as strategies to enhance motivation to treat the NDS with the seriousness it requires.

General feedback on outcomes measures

Language

The language of the identified outcomes appears to reflect vision statements rather than outcome statements. In addition, many of the indicators seem to lack clarity.

Council recommends that outcome statements:

- Are unidimensional measuring one identifiable outcome at a time
- Are clustered to provide a picture of the issue under investigation
- Reflect something that has happened rather than opportunities e.g. 'I have a job' rather than '*I have employment opportunities*', '*I go to the library where I feel welcome*' rather than '*I can access social and cultural events*'
- Reflect the breadth of meaning required e.g., the word *'accessible'* needs to reflect more than physical access and includes the many other adjustments that assist people with disability to participate such as technology, Easy Read formats, images for people with intellectual disability or CALD communities
- Have clear and precise meaning. Council members were completely uncertain as to what was meant by: '*I have access to communications and information networks*'
- Are specific: '*I have supportive relationships*' would be better measured as *'I have someone to call on for practical assistance / I have someone to call on for emotional assistance / I have someone to call on in a crisis'*
- Describes elements that make its measurement clear – '*well-designed communities*' is abstract and subject to very different interpretation. '*I live in a community in which I can visit everywhere I want to'* is a specific question a respondent can answer
- Are responsive to variations across the lifespan.

Council recommends that indicators are:

- Behavioural, e.g., '*I vote*', rather than '*I participate in civil and political life*'
- Are open to non-binary responses
  - e.g., *I work - yes /no / as much as I want / as much as my peers*

- ○ include barriers to working more:
  - ▪ factors associated with self: *I am unable to work as much as I want due to my health*
  - ▪ other factors: attitudinal / lack of support in the workplace / availability of childcare, etc.

Social and accessible communities

Background

Housing is an issue of particular priority to Council for the next National Disability Strategy. 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 and governments at all levels.

The lack of accessible affordable housing has profound and compounding 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 on 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.

Specific commentary in relation to outcomes and indicators

The general commentary above provides feedback on terms such as *'well designed communities', opportunities for full inclusion* and *'I can access social and cultural events'.*

Additional outcome indicators and performance measures are required in the areas of digital access and participation in sport (e.g. collected by Sport Australia.)

Economic security

Background

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 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 to supported employment. In addition, 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 in addition to the obvious other social outcomes .

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.

Specific commentary in relation to outcomes and indicators

- Replace *I have employment opportunities* with *I have a job*
- Replace *financial stress* with *access to emergency funds*
- Additional measures of interest include measures of:
    - Transition from supported to open employment
    - Perceived adequacy of support in finding and retaining employment
    - Annual reporting of rates of employment of people with disability within Federal, State and Territory public service organisations
    - Annual qualitative reporting of changes made to recruitment processes to 'level the field' for people with disability within all public sector organisations
    - Comparative wage outcomes for people with disability in same way gender disparity is measured.

Health and wellbeing

Background

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[1] 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.

Specific commentary in relation to outcomes and indicators

- Replace 'accessible' with 'responsive' in *My GP, hospital and other health care providers are accessible*.

---

[1] 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

- Ensure reporting enables the demonstration of stark health inequalities[2] when compared with the general population (featured in the Council's submission), and extend the measurement and reporting to people with disabilities other than intellectual and cognitive disabilities. Reporting should include data that allows comparison of rate of:
  - number of health problems
  - avoidable deaths
  - early indications of future increased ill-health such as obesity and psychiatric disorder
  - under-diagnosis of chronic and acute health conditions that can lead to significant functional impacts
  - potentially modifiable cardiometabolic risk factors
  - consultations with GPs addressing physical and preventative health issues
  - prescription of preventative health medications
  - prescription of psychotropic medication
  - usage of emergency departments and hospital admissions
  - potentially preventable hospitalisation
  - mental health admissions
  - contacts with community mental health services
  - premature death.
  - readmissions to hospital
- Additional data collection and monitoring for outcomes is required in the following areas recommended in the Council submission:
  - use of Medicare items that provide extra time for treatment of people with disability (recommendation for Services Australia)
  - health status of people with disability (recommendation for the Australian Bureau of Statistics/Australian Institute of Health and Welfare)
  - review of deaths focused on both the health system and the disability support system (recommendation for National, State and Territory Attorneys General)
  - GPs use of comprehensive, high-quality, annual health assessments to people with disability (recommendation for COAG Health Ministers Conference (or its equivalent)

---

[2] 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 Final systemic advocacy report - deaths in care of people with disability in Queensland February 2016

     ○ ensuring all health initiatives have a positive impact on people with disability. (recommendation for COAG Health Ministers Conference)

Rights protection

Background

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 disability providers and under the interface principles, state justice departments are required to continue 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 for 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.

Specific commentary in relation to outcomes and indicators

- Ensure that measures in relation to access to justice include:

  ○ people with disability having their statements taken / get into court / being supported through court system / % advisors as people with disability / % of women with disability having their children removed

  ○ every police report taken must record disability

  ○ percentage of prisoners who have intellectual disability, cognitive impairment or psychosocial disability

  ○ people with disability who have been identified, diverted from the criminal justice system or redirected to non-custodial order

Learning and skills

Learning and skills are challenging areas for the development and monitoring of outcomes because it is a domain in which there is no commonality of language and many jurisdictions appear to deliberately divert measurement, for example by describing all schools (including support classes and schools for specific purpose (SSPs) as inclusive.

This is a domain in which specific measures with behaviourally defined indicators may be required. This would mean, for example, that in the area of school education, outcomes would not indicate inclusive education but ask questions related to setting, adequacy and responsiveness of support and feeling of welcoming / belonging.

Specific commentary in relation to outcomes and indicators

The indicators identified do not clearly relate to the outcome measures.

Outcomes and indicators are required in the area of employment related education and training such as *'I have access to training to get the job I am capable of'; 'I have access to training to get a promotion and pursue a career'*.

Personal and community support

Specific commentary in relation to outcomes and indicators

- The distinction between '*I can access specialised disability services and supports I need including NDIS for eligible participants',* and '*I can access community-based supports'* will not be clear to most people with disability who do not make the distinctions between disability, community and mainstream supports in the way in which government does.

- Whilst co-design is a key recommendation in relation to the development of all outcome and indicator measures, co-design is especially critical in this domain where indicators are very vague and open to different interpretations.

Implementation of the outcomes framework to enhance the tracking of effectiveness

Leadership in government is critical to demonstrate that the implementation of the National Disability Strategy is core serious business of government. 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.

The Council's submission on the NDS included a number of measures to improve accountability of government for outcomes under the NDS. These measures include:

Co-design the NDS and outcomes measures with people with disability

Council calls upon the Department of Prime Minister and Cabinet, State and Territory Departments of Premier and Cabinet, all government departments and local government to re-establish and strengthen leadership by people with disability and to strengthen the capacity for co-design of the NDS and the collection, disaggregation and publication of outcome measures related to people with disability.

Annual report to Parliament

Council calls upon the Prime Minister and the Premiers and Chief Ministers to deliver an annual report to Parliament on the achievements under the Strategy.

Requirement that all legislation to be viewed through a disability lens

Council calls upon all National, State and Territory Governments to 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).

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

Council calls upon the Department of Prime Minister and Cabinet to support the proposal of the Productivity Commission into the National Disability Agreement, that commitments and obligations of governments under the new National Disability Agreement be reflected in the other Commonwealth–State Agreements (including National Partnerships).[3]

Collection, dissemination and reporting on data that reflect changes in outcomes

---

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

Council recommends that:

- there are increased questions related to disability in the census
- all data collected is disaggregated by disability, disseminated and reported. This includes but is not limited to health related data, employment and income related data, data collected by the Australian Prudential Regulation Authority (APRA) and the Australian Charities Commission
- clusters of measures are developed to operationalise broad concepts such as 'opportunity for social participation'
- all government programs identify and monitor data related to the impact of programs on people with disability
- key indicators that align with quality of life domains be developed across all government departments to provide the basis for identifying need, allocating funding and resources and monitoring change over time; and that measures are consistent with international measures and indicators used by OECD countries to track progress with other OECD countries.