

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

Public consultation

Make a submission

Part B – Improving outcomes for people with disability

This section asks about what you think is most important to measure to show progress in achieving outcomes for people with disability under the new National Disability Strategy (the Strategy) and the National Disability Insurance Scheme (NDIS).

All questions are optional.

Outcome areas (also called Domains)

Based on feedback from stage one consultations on the new Strategy, it is proposed that the existing outcome areas are retained as part of the new Strategy and the Strategy and NDIS Outcomes Frameworks. These are:

1. Inclusive and accessible communities
2. Economic security
3. Rights protection, justice and legislation
4. Personal and community support
5. Learning and skills
6. Health and wellbeing.

Monitoring and reporting progress against the Strategy and the NDIS is vital to ensure that life is improving for Australians with disability. It is important that we develop comprehensive and appropriate performance indicators and measures that reflect areas that really matter in achieving outcomes under the six outcome areas for people with disability.

The following questions ask you to tell us what you think is most important to measure progress in improving life for people with disability under each of the outcome areas of the Strategy and NDIS Outcomes Frameworks.

Question 1:

What matters most to measure and report on as we seek to achieve inclusive and accessible communities for people with disability?

The **inclusive and accessible communities** outcome aims for people with disability to live in accessible and well designed communities with opportunity for full inclusion in social, economic, sporting and cultural life.

Inclusive and accessible communities may include, ease of access to public buildings, moving freely about the local community using public or private transport and having access to communication and information networks.

Please provide your response to Question 1 in the space provided below (300 word limit).

AHPA supports the sub-outcomes and example indicators proposed for Domain 1. We note that there are examples of significant success under the NDIS (or Scheme) where participants have been supported to access social and community activities as well as more accessible and flexible housing arrangements. However, practitioners continue to report significant disparity across the Scheme in terms of the supports and services that participants are able to access, which can significantly impact their ability to participate in their communities or live independently in the way that they wish. That disparity is based on a range of factors including the participant's location, socioeconomic status, education and capacity to self-advocate as well as their cultural background. AHPA also argues that while the introduction of the NDIS has improved opportunities for many within the Scheme, it may have reduced opportunities for those outside it in relation to their ability to participate in and access the community. This is due to the shift to private, fee-for-service models that those outside the Scheme are unlikely to have access to. On the basis of this, we argue that reporting on the indicators needs to provide sufficient granularity to ensure that outcomes information can be reported on for different cohorts of people with disability. We recommend engagement with participants and providers in relation to defining the different cohorts that should be reported on as they'll be best-placed to advise where they are aware of disadvantage. We also argue that outcomes reporting should seek to address not only Scheme participants, but also those people with disability not deemed eligible for the NDIS and only able to access Commonwealth and jurisdiction-funded services. We recognise the challenge of reporting on the latter group, due to the relative lack of government-funded supports available to them. It is likely that further work will be required in conjunction with community organisations and disability organisations representing consumers in order to begin developing ways to measure outcomes.

AHPA also notes that while some of the indicators fall within the remit of the NDIA and should be relatively achievable in terms of measurement and reporting, a range of others such as access to community resources, participation in political and civic life, representation in roles of influence, while highly relevant, will likely require significant work and funding to develop benchmarks, measures and data gathering capacity, as well as clear accountability and/or ownership of responsibility for outcomes measurement. We argue that it may be appropriate to have a staged rollout of indicators, based on how achievable reporting on individual indicators is. A process of prioritization and reviewing capacity may be appropriate across all domains and outcomes measures.

Question 2:

What is most important to measure and report on as we seek to achieve economic security for people with disability?

The **economic security** outcome aims for people with disability to have economic security and suitable living arrangements, enabling them to plan for the future and exercise choice and control over their lives.

Economic security may include more people with disability have a job, have enough income for daily living expenses, are not living in poverty, and have somewhere suitable to live.

Please provide your response to Question 2 in the space provided below (300 word limit).

AHPA supports the sub-outcomes and example indicators in Domain 2. This is an important domain as part of an overall focus on economic security for people with disability, given their significant economic disadvantage compared to the broader community. We also support the need to measure financial stress both in terms of short-term stress and ongoing stress that may arise from dependence on government supports such as the Disability Support Pension and carer payments which can leave people with disability particularly exposed to policy shifts and changes in determinations of eligibility for supports. We argue that there is a need to report on general perceptions of economic security for people with disability and consider how income security could be improved as we understand this to be a source of considerable

stress. We note the need to report on broad disability cohorts including intellectual disability and psychosocial illness, noting the potential differences between these groups, as well as across geographic regions, noting the additional impact of economic insecurity where social support structures are less developed.

We further note that people with disability are often reliant on the economic support of families and that this makes consideration of economic security something that needs to be considered as a whole rather than just in relation to the person with disability. We note that the economic security of people with disability may be particularly impacted at key family life stages such as when a parent retires or even passes away. This makes reporting on the economic security, including financial insecurity and stress, of families and informal carers an important aspect of any reporting of outcomes measures.

AHPA also notes that labour force participation remains low for people with disability, particularly in the mainstream workforce. We argue that an additional indicator in relation to mainstream labour force participation should be created to encourage a focus on this aspect of employment. We further argue that outcomes reporting should be split across the various Departments and Agencies with responsibility for this to ensure accountability and awareness of their role in achieving improved outcomes in relation to employment.

Finally, we note that homelessness for people with disability often results from poor coordination and support between housing services and other support services, including NDIS-funded services. We note the success of programs such as the Aboriginal Tenancies at Risk program in Victoria and argue for that there should be some measurement of access to programs to help avoid homelessness.

Question 3:

What is most important to measure and report on as we seek to achieve health and wellbeing outcomes for people with disability?

The **health and wellbeing** outcome aims for people with disability to attain highest possible health and wellbeing outcomes throughout their lives.

Health and wellbeing may include, interacting with health professionals who understand needs of people with disability, affordable health services and satisfactory mental health support.

Please provide your response to Question 3 in the space provided below (300 word limit).

AHPA very strongly supports improved measurement of outcomes in relation to the health and wellbeing of people with disability and the sub-outcomes proposed. In this context it will be essential to measure and report on access to allied health services as well as medical services. We note for example that while a GP management plan might be an important first step in addressing a chronic illness, it is the ongoing support of allied health professionals that is likely to ensure that the person with disability or their family and carers are able to manage that chronic illness. A key aspect is ensuring that the health professional understands has sufficient time with the person with disability and their family and is able to support them in building capacity to manage their health and wellbeing.

People with disability are disproportionately likely to experience chronic illnesses and mental ill-health, as well as potentially experiencing a range of health needs arising from their disability. People with disability are also particularly impacted by the coordination of care across health services including both primary care services and discharge processes from acute settings into community-based care. A range of recent reviews have shown significant gaps in the accessibility of health services in the community, particularly allied health services where there is a strong dependence on private health insurance or the capacity to pay privately. Some improvements have been made to the interface between the health and disability systems through Disability Reform Commission-led changes to agreements about responsibility for disability-related health supports but interface issues and shifting of responsibility continue to impact people with disability, particularly with the recent increased focus on cutting costs within the NDIS. One of the most challenging areas appears to be the question

of addressing the mental ill-health of a participant where this is not their primary disability (i.e. they are not considered to have a psychosocial disability).

AHPA argues that there is not enough data recorded about the rates of chronic and mental illness among people with disability, nor the extent to which people with disability are able to access the services they need. This is particularly the case for post-diagnosis services such as might be provided by allied health practitioners, and which represent an important support to assist people in managing their chronic condition or mental health. As these are often not funded by Medicare, we argue that data should be measured across other publicly funded services such as community health services, as well as services purchased privately or paid for by private insurance. To measure outcomes meaningfully, it will be necessary to improve capacity to measure service use and outcomes across allied health, general practice and acute care. We note that general practice and acute care have had significant work undertaken to create the infrastructure for measuring outcomes but similar work has not yet been undertaken to support the capacity to better understand usage and outcomes across allied health services. This work is likely to require some initial investment to develop minimum datasets and outcome measurements and to support scalable pilots.

Question 4:

What is most important to measure and report on as we seek to achieve rights, protection, justice and legislation outcomes for people with disability?

The **rights protection, justice and legislation** outcome aims for people with disability to feel safe and have their rights promoted, upheld and protected

Rights protection, justice and legislation may include feeling safe, the ability to participate in democratic processes and being free from disability related discrimination.

Please provide your response to Question 4 in the space provided below (300 word limit).

AHPA broadly supports the sub-outcomes and indicators outlined in Domain 4. However, feedback from practitioners working with people with disability shows that many find it hard to access advocacy services to help them understand what rights and outcomes they are entitled to, or to realise those rights and outcomes. A simple example of this is the significant variation found in the size of NDIS plans, and commensurate access to supports and services, for different cohorts of people with disability. The ability to self-advocate, and overall income and education levels of participants and their families and informal carers, continue to determine the extent to which participants can access services that they are entitled to. While the NDIA is working to reduce this variation, AHPA argues that this issue extends to all aspects of life for a person with disability and that a crucial indicator should be access to an advocacy or support person for the person with disability.

AHPA also reiterates our view that indicators should provide breakdowns across key cohorts of people with disability and across geographic regions.

Question 5:

What is most important to measure and report on as we seek to achieve learning and skills outcomes for people with disability?

The **learning and skills** outcome aims for people with disability to achieve their full potential through their participation in an inclusive, high-quality education system that is responsive to their needs. It also aims for people with disability to have opportunities to continue learning throughout their lives in both formal and informal settings.

Learning and skills may include, teachers who understand needs of people with disability, continued access to formal and informal learning settings, and preparation for transitioning from one level of education to the next, or from education to employment.

Please provide your response to Question 5 in the space provided below (300 word limit).

AHPA supports the proposed sub-outcomes and indicators in Domain 5 and considers the proposed sub-outcomes across learning and skills to be broadly appropriate. However, we are concerned that there is a stronger emphasis on participation than achievement, which creates a risk that organisations and funders do not seek to maximise outcomes for people with disability. While we recognise the challenge of creating consistent measures for people with varying disability and capacity, we believe this is important enough to justify the effort. As such we argue strongly for the need to measure and report on educational attainment across all levels of education, including vocational education with a focus on achieving maximal outcomes for people with disability.

The sub-outcome in relation to periods of transition (such as starting school) is a particularly important area to measure and track outcomes and consistency of outcomes. Practitioners report that times of transition present significant potential challenges for people with disability and their families. When poorly managed these can result in adverse outcomes and missed opportunities that can significantly impact the person and their longer term outcomes. The new proposals for independent assessments may further impact times of transition, particularly as their role in supporting planning remains untested. We argue that it will be important to benchmark current outcomes with outcomes achieved as part of the new assessment and budgeting process to ensure that NDIS participants going through periods of transition can access the right set of assessments and service planning activities, and the necessary plan budgets to support those.

AHPA also reiterates our view that disparities between those that can access the NDIS and those that can't should be captured in outcomes measurement to ensure that states and territories are working with the Commonwealth to reduce inequities. We strongly argue that data needs to be captured for areas such as participation in schooling and adult literacy for people with mild intellectual disability who are not able to access the NDIS.

Question 6:

What is most important to measure and report on as we seek to achieve personal and community support outcomes for people with disability?

The **personal and community support** outcome aims for people with disability, their families and their carers to have access to a range of well-coordinated and effective services and supports that are appropriate to their needs.

Personal and community support may include, access to specialised disability services and supports, including NDIS for eligible participants, community-based services that are available when and where they are needed and services that are well coordinated.

Please provide your response to Question 6 in the space provided below (300 word limit).

AHPA strongly supports the sub-outcomes and indicators identified, particularly as they relate to access. We strongly argue the need to measure and report data in relation to access to high-quality services for people with disability. There are currently significant limitations in the data available to determine market gaps and thin markets even with the NDIS. These gaps are exacerbated by the potentially significant differences between access for participants in the NDIS that are Agency-managed versus those that are plan- or self-managed arising from the high cost of registration with the NDIS Commission. Allied health providers, particularly those that have solo and/or part-time practices with lower volumes of disability services, provide consistent feedback that they cannot justify the cost of registration. The impact of this is largely on those participants that cannot access services from unregistered providers. This is an issue AHPA argues must be addressed as anecdotal feedback and advice from associations suggests that the providers choosing not to register are often the most experienced and with the highest demand for services.

While work arising from the BLCW program, including demand mapping, has sought to provide some access to information for the community and providers, and the NDIS has launched a thin markets program to identify and address gaps, there are still significant gaps in workforce and service data that must be addressed. We note that allied health practitioners may have a significant level of specialization and more granular data than simply profession data is essential. For example, an occupational therapist may specialize in assistive technology

prescription and would be of little value to a family seeking a paediatric occupational therapist to support a child with autism.

We also argue strongly for the need to better measure and report on differences in outcomes between people in different locations, with different income levels and with different cultural backgrounds. While there are significant questions about how the proposed independent assessment program will impact consistency of access, we acknowledge the work of the NDIS to provide a more consistent and equitable process. We argue that it will be important to measure and report on the effectiveness of this approach and to also report similarly on access to services for different cohorts that are outside the NDIS.

Allied health practitioners regularly provide feedback on the impact of the NDIS in relation to access to services for people that have been deemed ineligible for the NDIS. It is clear that the demand for services arising from the NDIS, and the lack of funding for services outside the NDIS, is restricting access for many people with disability. We argue strongly for the need to develop measures that can show the extent to which people with disability not eligible for NDIS funding are able to access services that meet their disability-related needs. For example, the move to shift funding of autism services from Medicare's Helping Children With Autism program to the NDIS, means that there will be families deemed ineligible for the NDIS that can no longer receive services to support their child. Yet it is not clear how this will be measured or addressed without specific work to develop capacity to identify and measure potential gaps in service access.

Question 7:

The National Disability Strategy and NDIS Outcomes Frameworks will track progress over time to determine whether the lives of people with disability are improving. Reporting against outcomes will help to inform where to prioritise and target investments.

How often would you like to see progress against the outcomes for people with disability in the National Disability Strategy and the National Disability Insurance Scheme reported?

Please provide your response to Question 7 in the space provided below (300 word limit).

AHPA calls for a combined annual report on outcomes for people with disability across both the National Disability Strategy and the NDIS. We argue that reporting annually provides a good balance given that there is still a significant amount of change occurring in the Scheme. One of the challenges with the NDIS is the rapid rate of change and it will be important to strike the right balance between reporting regularly and allowing changes to be embedded. However, AHPA also argues that the introduction of independent assessments represents such a significant potential change for people with disability that it may be appropriate to introduce an extra targeted report that addresses those areas of the outcomes impacted by the introduction of independent assessments. This will be an important means of evaluating and providing confidence in the process for the broader disability sector. This would be an additional report focused on key areas such as access for all types of disability and across different geographic locations and cultural backgrounds as well as the measures relating to access and consistency for current participants.

In addition to formal reporting processes, AHPA strongly argues for publicly accessible dashboards or equivalent to enable people with disability and the broader community to access outcomes data with sufficient granularity to address areas such as those outlined in our responses to the individual domains. This reflects the proposals in the recent National Disability Strategy consultation paper.

Make a submission

Part C – Additional information

Consultation on the approach to measuring, monitoring and reporting of the effectiveness of the new National Disability Strategy and the National Disability Insurance Scheme will inform:

- the structure of the National Disability Strategy and the National Disability Insurance Scheme outcomes frameworks
- implementation of the National Disability Strategy and the National Disability Insurance Scheme outcomes frameworks

Question 8:

Is there anything else that you think should be considered when we are monitoring and measuring the impact of activities on people with disability?

Please provide your response in space provided below (1000 word limit).

Allied Health Professions Australia (AHPA) thanks the Department of Social Services (DSS) for the opportunity to comment on the *Improving outcomes for people with disability under the National Disability Strategy and the National Disability Insurance Scheme* consultation paper. The allied health sector is a key provider of services for people with disability and an important partner in supporting National Disability Insurance Scheme (NDIS) participants and other people with disability to achieve the outcomes they are seeking.

While our submission provides specific responses in relation to the individual domains and the outcomes and indicators listed against those, we wish to reiterate our strong belief that the Vision should be adjusted to more explicitly acknowledge the need to achieve outcomes and success for all people with disability, regardless of their culture or background. While we acknowledge that this may be intended by the statement, the current failures of the system in relation to those that fall outside the NDIS and the access issues experienced by Aboriginal and Torres Strait Islanders and culturally and linguistically diverse (CALD) communities must be a key priority. By enshrining the needs of those communities in the vision, we argue that people with disability, and the disability sector, will have greater confidence in the work of DSS and Australian governments.

AHPA strongly reiterates our view that there needs to be investment in developing the infrastructure for better measurement and reporting of relevant workforce and outcomes data in the disability sector. We note the significant investment undertaken in relation to data gathering and linking of data for medical services across parts of the health sector, focused primarily on general practice and acute services. These initiatives provide an important foundation for policy and program development. Yet AHPA is not aware of any structured focus on equivalent allied health and other services for people with disability. Without this work, workforce and other policy initiatives will always be hampered by a lack of data. Similarly, research work to support high quality services for people with disability will be limited by that lack of data.

Thank you for taking our survey. We really appreciate you taking the time to tell us your thoughts and opinions. We will use this information, along with information from stakeholder workshops and roundtables, to inform the development of the NDS and NDIS Outcomes Frameworks.

If you have any questions or feedback about this survey, please contact the Department of Social Services via disabilityreform@dss.gov.au.