



CRE-DH

Centre of Research
Excellence in
Disability and Health

ENHANCING AND MONITORING EQUITY WITHIN THE CONTEXT OF THE NDIS

Submission to the National Disability Insurance Scheme Review

May 2023

in partnership with



About this submission

This submission is made on behalf of the Centre of Research Excellence in Disability and Health (CRE-DH) funded by the National Health and Medical Research Council, 18 May 2023.

The submission is in response to the independent review of the National Disability Insurance Scheme announced by the Australian Government on 18 October 2022.

Dr Alexandra Devine ^{1,2}

Dr George Disney ^{1,2}

Professor Emerita Gwynnyth Llewellyn ^{1,2,3,9}

Professor Anne Kavanagh ^{1,2}

Professor Helen Dickinson ^{1,4}

Professor Jennifer Smith-Merry ^{1,3}

Dr Nicola Fortune ^{1,3}

Dr Sophie Yates ^{1,5}

Professor Emeritus Roger Stancliffe ^{1,3}

Professor John Gilroy ^{1,6}

Professor Luis Salvador-Carulla ^{1,7}

Alex Sully ^{1,2}

Dr Samia Badji ^{1,8}

Dr Kim Bulkeley ^{1,3,6,9}

¹ Centre of Research Excellence in Disability and Health

² Melbourne School of Population and Global Health, The University of Melbourne

³ Centre for Disability Research and Policy, The University of Sydney

⁴ Public Service Research Group, UNSW Canberra

⁵ Crawford School of Public Policy, Australian National University

⁶ Faculty of Medicine and Health, The University of Sydney

⁷ Health Research Institute, University of Canberra

⁸ Centre for Health Economics, Monash University

⁹ WHO Collaborating Centre for Strengthening Rehabilitation Capacity in Health Systems

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About the CRE-DH

The Centre of Research Excellence in Disability and Health (CRE-DH) aims to identify cost-effective policies to improve the health of people with disability in Australia. There are four interconnected research areas the CRE-DH focuses on:

- mapping the health inequities between Australians with and without disabilities,
- analysing the social, economic and environmental factors that contribute to the poorer health of people with disability,
- modelling the cost-effectiveness of health policy interventions, and
- policy analysis and reform.

The CRE-DH is an interdisciplinary research group comprised of academics from five universities, a team of international advisors and a Partner Advisory Group of stakeholders from the disability and health sectors. The CRE-DH Co-Directors are Professor Anne Kavanagh (University of Melbourne) and Professor Emerita Gwynnyth Llewellyn (University of Sydney). The CRE-DH includes Chief Investigators from the University of Melbourne, University of Sydney, Monash University, UNSW Canberra and RMIT with multidisciplinary skills in epidemiology, health economics, health and social policy, psychology, psychiatry, public administration and public health. In addition, we have Associate Investigators from a range of national and international universities and the World Health Organization. We work in collaboration with key stakeholders including DSS, ABS, AIHW and peak bodies in the disability advocacy and service sector through our Partner Advisory Group. Several members of the CRE-DH research team and the Partner Advisory Group also have lived experience of disability.

Centre of Research Excellence in Disability and Health

The University of Melbourne VIC 3001

cre-dh@unimelb.edu.au

credh.org.au

[@DisabilityHlth](https://www.facebook.com/DisabilityHlth)

EXECUTIVE SUMMARY AND RECOMMENDATIONS

In our research, we use the term equity to refer to fairness. Persistent structural inequities are experienced by many Australians with disability across numerous life domains (e.g., employment, education) contributing to inequitable outcomes (e.g., life expectancy, mental health) when compared to Australians without disability ([Fortune et al., 2021](#)). The National Disability Insurance Scheme is an important policy reform for reducing inequities and therefore unfairness between Australians with and without disability, yet it also has the potential to exacerbate inequities between different groups of people with disability including between individuals receiving NDIS plans and those who do not. Understanding where inequities are exacerbated or reduced by the NDIS is critical to understanding how outcomes can be improved for the diversity of NDIS participants and Australians with disability more broadly.

This submission draws on evidence from research conducted by the Centre of Research Excellence in Disability and Health (CRE-DH) researchers and affiliates. We highlight our work in two key areas of concern to the NDIS Review:

- equity within the NDIS in relation to access, plan budgets and spending, and experiences;
- approaches to enhance the monitoring and reporting on the effectiveness and equity of the NDIS.

RECOMMENDATIONS

Actioning the following 12 recommendations are critical to ensure NDIA public accountability for best efforts at reducing inequities within the context of the NDIS. All recommendations are based on our research, which is outlined in more detail in the main body of the report.

To tackle inequities we found within the NDIS, we recommend:

1. Invest in quantitative and qualitative research to not only monitor inequities in access to the NDIS, plans and services, but also to produce high quality evidence on what is driving inequities according to socio-economic and disability characteristics, Indigeneity, ethnicity, gender and geographical location (e.g., rural, remote).
2. Prioritise NDIA work on co-design to understand and address specific barriers to equitable NDIS access and engagement. The co-design needs to be based on best practice models that enable all parties to participate fully in the co-design process.
3. Enhance NDIA accountability to provide easily accessible, transparent, and real-time information and support to people with disability, their families and representative organisations to enable them to understand and equitably navigate the NDIS.
4. Invest in further staffing the NDIS with people with lived experience of disability, their family and supporters, and from communities more likely to experience barriers to equitably engaging and participating in the NDIS. These include people with psychosocial disability, and from Aboriginal and Culturally and Linguistically Diverse communities.
5. Require NDIA to regularly publish robust data on Scheme access, determination of budgets and plans, progress in the Scheme and achievement of outcomes within and across groups of participants. Key differences between groups should be appropriately adjusted for in all analyses by NDIA and external researchers to ensure comparisons are like with like.
6. Require the NDIA to collaborate with State and Territory governments and other Commonwealth Departments to ensure people with disability who are and who are not NDIS plan participants have access to evidence-informed, easily accessible, affordable services

and supports (e.g., allied health, mental health support).

7. Require the NDIA to publish regular data related to the functioning of local markets and the actions being taken within stated timelines to resolve issues related to thin markets and bottlenecks in access to equipment, Assistive Technology and home modifications.
8. Invest in improving access to quality support coordination.
9. Invest in strategies to stimulate and monitor the availability of a quality, values driven and sustainable place-based workforce to match the varied disability, geographical location, mental health and cultural needs and preferences of NDIS participants.

Monitoring inequities and effectiveness of outcomes

10. Develop and adopt standard terminology, consistent approaches, and robust measures to monitor and report on the availability of services in local markets. Review of the NDIS Outcomes Framework should be informed by the [CRE-DH Disability and Wellbeing Monitoring Framework](#).
11. Develop and adopt standard terminology, consistent approaches, and robust measures to monitor and report on provider-level outcomes data.
12. Invest in a secure platform where qualified (e.g., [Five Safes Framework](#)) researchers can access unit record detailed data on NDIS participants. The NDIA should also transfer more detailed data to ABS for linkage into MADIP. This would enable inequities in outcomes and their causes between NDIS participants; people with disability without NDIS packages; and people without disability more broadly to be understood, monitored over time and reported.

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1. Equity within the NDIS

Much of our NDIS research has focused on people with disability more likely to experience barriers in accessing and navigating the NDIS ([Devine et al., 2021](#)). This includes (but is not limited to) participants with psychosocial disability, and participants from Culturally and Linguistically Diverse (CALD) backgrounds, and participants who identify as Aboriginal and Torres Strait Islander. Our evidence is presented in relation to 1) Gaining access to the NDIS; 2) NDIS plan sizes and spending; and 3) Factors influencing NDIS experiences in relation to attaining outcomes in line with participant needs and aspirations.

1.1. Gaining Access to the NDIS

Gaining access to the NDIS is particularly challenging for people with psychosocial disability Aboriginal people and people from Culturally and Linguistically Diverse communities.

Our research has identified the following common barriers experienced by people with psychosocial disability ([Smith-Merry et al., 2018](#); [Hancock et al., 2019](#); [Hancock et al., 2022](#); [Devine et al., 2021](#)), Aboriginal people ([Barney et al., 2023](#)) and people from CALD communities ([Devine et al., 2021](#)):

- Inconsistent understanding across the NDIA of the interacting factors influencing functioning and experiences of disability (e.g., relationships between mental health, disability and recovery; compounding life inequities; and diverse cultural understandings and conceptualisations of disability).
- Key information and communication about the NDIS especially how to access the Scheme was often confusing and not readily accessible to all individuals and communities, particularly for people for whom English was not their first language or who use Auslan.

- Insufficient resourcing, availability and capacity of supports (formal and/or informal) to help individuals to navigate the often complicated, inflexible and potentially harmful access process (e.g., undermining mental health) and gather the evidence they require to demonstrate eligibility. This was particularly so for people with unmet basic (and complex health/mental-related needs e.g., housing).
- Personal beliefs, fears and experience of stigma and discrimination within systems, including the NDIS, hindered willingness and capacity of many individuals to access and interact with the NDIS.
- Concern that even if access is gained, the NDIS was not able to meet the intersecting mental health, cultural and disability needs of all participants.
- Accessing the Scheme required medical evidence and sometimes allied health reports which applicants needed to pay for themselves.

Individuals who are not able to access NDIS funding have lost access to previously accessed programs.

Inequities are compounded for individuals with disability that are not able to access the NDIS. In our research, this is particularly evident for people with psychosocial disability ([Hancock et al., 2019](#); [Devine et al., 2021](#)). For example, research with 41 nation-wide community-based mental health organisations re-iterated the barriers people with psychosocial disability experienced in trying to access the NDIS, alongside the often-dire impact of not being able to access previously funded supports when Commonwealth program funding (e.g., Partners in Recovery, PHaMs and D2DL) transferred across to the NDIS ([Hancock et al., 2019](#)).

This evidence underscores the urgent need to examine how to re-instate access to previous wide-scale evaluated programs, such as Partners in Recovery for people with and without NDIS plans. both

We recommend:

1. Invest in quantitative and qualitative research to not only monitor inequities in access to the NDIS, plans and services, but also to produce high quality evidence on what is driving inequities according to socio-economic and disability characteristics, Indigeneity, ethnicity, gender and geographical location (e.g., rural, remote).
2. Prioritise NDIA work on co-design to understand and address specific barriers to equitable NDIS access and engagement. The co-design needs to be based on best practice models that enable all parties to participate fully in the co-design process.
3. Enhance NDIA accountability to provide easily accessible, transparent, and real-time information and support to people with disability, their families and representative organisations to enable them to understand and equitably navigate the NDIS.
4. Invest in further staffing the NDIS with people with lived experience of disability, their family and supporters, and from communities more likely to experience barriers to equitably engaging and participating in the NDIS. These include people with psychosocial disability, and from Aboriginal and CALD communities.

1.2. Equity in relation to NDIS plan sizes and spending

Utilisation rates on their own are an ineffective indicator of NDIS effectiveness, given the range of different factors that impact utilisation.

A 2021 review by [Dickinson and Brown](#) of international individual funding schemes for disability support services demonstrated large variation in budget utilisation rates around the world (between 42 and 99%) with disparities within schemes across geographical areas, system maturity and cultural group. Like the findings from qualitative research conducted by Devine et al. ([2021](#)), the review identified a wide range of factors that impact on ability to utilise budgets (e.g., lack of support and planning, complex systems, lack of providers, lack of information around quality amongst others, retaining funds due to fear of having insufficient funds in the future). Therefore, on their own utilisation rates are an ineffective indicator of effectiveness, however, the Dickinson and Brown review noted that a 100% utilisation rate would generally indicate something is wrong with care planning or budget allocation processes, such as insufficient funding allocation to meet needs.

The NDIS planning process appears to be taking account of social disadvantage for some groups, although not others, through provision of larger plans.

Quantitative analysis commissioned by the Department of Social Services and led by Disney et al. ([2021](#)) examined whether Aboriginal participants, participants from CALD communities and participants living in low socio-economic areas experienced inequalities in relation to plan sizes and spending. Key results demonstrated that:

- *Aboriginal and CALD participants had larger plans than the rest of the population, even after considering other drivers of plan size (e.g., age, disability group, disability severity, socio-economic Status), indicating that the NDIS appeared to recognise these groups may need more funded services and supports.*
- *For Aboriginal participants, however, higher plan sizes were not matched by higher levels of spending. This was a pattern exhibited across NDIS disability types (e.g., children*

with autism, and adults with intellectual and psychosocial disability) and in both urban and rural areas, especially for capacity building supports.

Quantitative statistical modelling for the Victorian Government that adjusted for key socioeconomic and disability characteristics led by Disney et al. (2021) identified the following inequalities within the NDIS:

- *Participants who live in rural and remote areas* received less funding in their NDIS plans, while also spending less of their allocated funds.
- *Individuals in receipt of funding through previous disability systems* received larger amounts of funding in their first NDIS plans compared to those with no prior access to previous funding.
- *Aboriginal participants on average received larger plans* when compared to non-Aboriginal participants, but again larger plans did not lead to higher spending.
- *CALD participants* generally received slightly larger plans and spend more of their plans when compared to their non-CALD counterparts.

We recommend:

5. Require NDIA to regularly publish robust data on Scheme access, determination of budgets and plans, progress in the Scheme and achievement of outcomes within and across groups of participants. Key differences between groups should be appropriately adjusted for in all analyses by NDIA and external researchers to ensure comparisons are like with like.

1.3. Factors influencing NDIS experiences in relation to attaining outcomes in line with needs and aspirations.

Equity in plan sizes does not always equate to equitable spending or outcomes.

Qualitative interviews with [Victorian NDIS participants conducted alongside the quantitative analysis](#) provided lived experience perspectives on factors contributing to the trends observed within the above quantitative results. Overwhelmingly in our interviews we found greater NDIS plan utilisation improved access to services and supports to help participants meet their disability related needs. This in turn created opportunities for enhanced independence, community participation, and enriched interpersonal relationships. Prior experience of disability systems also enabled individuals to engage more easily with services and utilise their funds. Yet, key findings demonstrated effective plan spending was still undermined for many by:

- *Limited availability of quality services and supports* was identified as the most direct barrier preventing participants from spending the funding in their plans as the services and supports they required were not always available or of sufficient quality. This problem was more acute the further a participant lived from Melbourne.
- *Delays in spending in one area* (e.g., core supports) led to challenges in utilising other components (e.g., capacity building) in the plans.
- *Delays and challenges in access, planning and review processes* - including experiences of negative treatment within participant engagement with NDIS frontline workers. This contributed to deteriorations in conditions which in turn led to difficulties in utilising plans to meet changing needs.

- *Negative treatment and exploitation* when engaging with service providers, alongside challenges in reporting such treatment (e.g., fear of losing services, delays in having complaints followed-up or appropriately handled).
- *Extensive delays in access and procuring* equipment, assistive technology and home modifications.
- *Many participants wanted more opportunities* to engage in more innovative and mainstream opportunities. This was particularly evident among participants who were engaged in previous systems and hoped that the NDIS would enable greater community involvement and life opportunities.

These barriers were further compounded by intersecting challenges experienced by participants with psychosocial disability, Aboriginal participants, and CALD participants ([Moskos et al., 2021](#)). Similarly, research undertaken by Gilroy et al. ([2018](#); [2020](#); [Dew, 2019](#)) on the NDIS planning process in regional, rural, and remote regions of NSW and Central Australia found that the NDIS planning process contributed to increased inequities for Aboriginal people in these areas.

The original intent of the NDIS was to ensure that the socio-cultural needs of Aboriginal people with disability were considered in the development of NDIS plans. The findings demonstrated slow progress to date on this even though Aboriginal people represent close to 10% of all plan holders. Thin-markets made it difficult for Aboriginal participants to use their plans, which in-turn contributed to planning reviews that often were reported to result in reduced funds, further undermining access to services and supports for Aboriginal people with disability ([Gilroy et al., 2018](#); [Gilroy et al., 2020](#); [Moskos et al., 2021](#); [Barney et al., 2023](#)). The NDIS workforce is in serious need of training on how NDIA engagement and decision making can impact on the lives of families in receipt of the NDIS. In addition, some of the Aboriginal participants experienced cultural discrimination from NDIA and LAC workers.

It is important to distinguish between people with high functional needs, who often have high utilisation of their NDIS plans, and those with complex intersecting needs, who have poor plan utilisation. Complex needs are often intersectional and typically create additional complexities, for example in relation to transition from inpatient care or jail into the community, behavioural support needs, alcohol and other drug needs, family, housing and placement breakdown ([McKenzie & Smith-Merry, 2023](#)).

Research led by Smith-Merry has demonstrated that people with complex disability support needs face inequities accessing the services they need, in part attributable to the individualised nature of the NDIS ([McKenzie & Smith-Merry, 2023](#)). This research found that poor service coordination for this group leads to people being unable to access NDIS supports and can mean that they are unnecessarily held in jail or hospital or at risk of losing existing housing. The notion that multiple disability and mainstream services can come together through the individual does not accord with the experiences of individuals who understandably find it difficult to facilitate multiple services themselves.

This research also found that plans were not able to be used to support integrated care where that care required them to access services outside of the NDIS. This was because the funding architecture of the NDIS and interfacing systems didn't allow for sufficient coordination across services and systems coordination. This means that people with complex needs couldn't use plans on par with others. Exacerbating this inequity was the withdrawal of existing strategies to address coordination of plans and implementation of plans for people with disability with complex support needs.

This and other research by Smith-Merry et al has shown that difficulty coordinating services for people with complex needs was particularly marked for people in rural and remote areas, those with psychosocial disability and Aboriginal participants ([Smith-Merry et al., 2023](#)). This contributes to further increasing inequities within the Scheme.

Women’s experiences of disability and accessing support services for people with disability are inevitably influenced by structural gendered inequalities.

Research led by CRE-DH affiliate Yates, investigated women’s experiences in relation to the NDIS ([Yates et al., 2021](#); [Yates et al., 2022](#)). The research findings highlighted the high administrative burden and associated stress of navigating the NDIS for women with disability. It noted this burden was particularly challenging for NDIS participants who were also primary carers of young children or family members with disability, and that such caring responsibilities were far more likely to be undertaken by women with disability than men.

Participants in this study also described the difficulties associated with the constant need to self-advocate for NDIS support and the people they support. For gendered reasons (i.e., men are recognised as more likely to benefit in situations relying on self-advocacy), self-advocacy processes are recognised as often more challenging for women to successfully navigate when compared to men ([Yates et al., 2022](#)). This raised concern that women - particularly those without sufficient social and financial capital - may experience more challenges accessing the NDIS and advocating for appropriate plans compared to men. This was especially troubling in the context of underfunded and overwhelmed disability advocacy services. In addition, this research raised concerns that the disparity in participation rates between men/boys (61%) and girls/women (37%) was not fully explained or justified by sex-based disparities in the prevalence of autism and developmental delay.

Enhanced support coordination may support participants to more effectively use their NDIS funded plans.

To assess if participants could be better supported in spending their allocated plans, Disney et al. ([2021](#)) modelled the impact of a range of support coordination scenarios on utilisation inequalities. Causal modelling established, that under a scenario where participants use at least 80% of their planned support coordination, there would be

increased use of capacity building supports, and in some circumstances core supports. Yet [qualitative interviews with Victorian NDIS participants](#) conducted alongside this modelling found that several intersecting barriers (e.g., limited supply of quality support coordinators, challenges navigating interface between systems) would need to be addressed to enable participants to first of all access sufficient quality support coordination, and then to gain support to access capacity building supports in the context of insufficient supply within the NDIS market.

Research led by McKenzie and Smith-Merry demonstrated that a significant factor in poor NDIS outcomes (e.g., poor plan usage, housing breakdowns, risk of unnecessary hospitalisation) was due to poor coordination of services ([McKenzie & Smith-Merry, 2023](#)). The research demonstrated that improving the quality of support coordination, required a wide range of actors often over an extended period, and cannot be supported through NDIS plans alone ([McKenzie & Smith-Merry, 2023](#)). They noted that sustaining collaborative approaches across jurisdictions, however, proved difficult. For example, an evaluation of a NSW Government NDIS add-on for people with complex needs, the Integrated Service Response, which was designed to bring together services to negotiate and action strategies for individuals in crisis situations due to complexity, found such programs may be labour-intensive but successful in providing the required coordination of supports required by people with complex needs ([McKenzie & Smith-Merry, 2023](#)). Unfortunately, that specific program was discontinued, as have other similar add-ons such as the NDIS Exceptionally Complex Needs Initiative.

Support coordinators need a strong market to enable participants to access quality services and supports in line with needs and aspirations.

A long-noted challenge with respect to the operation of the NDIS is the issue of market stewardship. In many areas around the country the market is not sufficiently developed. This resulted in either a lack of available providers for

participants to purchase services from or a situation where providers may be available, but their offering was not sufficiently diversified to meet participant needs. This latter situation may be particularly relevant for individuals from CALD or Indigenous backgrounds ([Dickinson et al., 2022](#)).

Dickinson et al. ([2022](#)) developed a market capacity framework that can be used to identify the types of challenges that are present within particular markets. At present the NDIA uses a suite of measures to assess market performance (plan utilisation, provider concentration, choice and control, participants per provider, provider growth/shrinkage). While many of these measures are helpful in indicating where challenges might be occurring in markets, none of these are sufficiently granular to identify what the issues are within a local market ([Dickinson et al., 2022](#)). In further work, Dickinson et al. ([2022](#)) developed a functional network analysis tool that seeks to use NDIS data and that of local governments to help identify what the market challenges and limitations are specifically within a local market. This work is ongoing although currently limited by the quality of the available data. Nonetheless it provides a useful model to mapping market capacity and identifying where stewardship is required ([Guitierrez-Colosia et al., 2022](#)).

We recommend:

6. Require the NDIA to collaborate with State and Territory governments and other Commonwealth Departments to ensure people with disability who are and who are not NDIS plan participants have access to evidence-informed, easily accessible, affordable services and supports (e.g., allied health, mental health support).
7. Require the NDIA to publish regular data related to the functioning of local markets and the actions being taken within stated timelines to resolve issues related to thin markets and bottlenecks in access to equipment, Assistive Technology and home modifications.
8. Invest in improving access to quality support coordination.
9. Invest in strategies to stimulate and monitor the availability of a quality, values driven and sustainable place-based workforce to match the varied disability, geographical location, mental health and cultural needs and preferences of NDIS participants.

2. Monitoring inequalities and effectiveness of outcomes

Monitoring can be used to determine the effectiveness of policies and programs in upholding the rights of people with disability, monitoring Australia's implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (as required in Article 33) and holding governments to account for the commitment made under Australia's Disability Strategy 2021-2031 to ensure that people with disability can participate as equal members of society. Several factors influence the ability of the NDIA, governments and researchers to adequately monitor inequalities and the effectiveness of outcomes within the context of the NDIS and beyond.

Research into equity of the NDIS is constrained by limitations in access to quality data on NDIS participants and markets.

Currently, access to longitudinal unit record anonymised NDIA data is provided to researchers on a project-by-project basis. This data is incredibly valuable: it has been used to produce the results of some of the studies cited in this submission. To enable further research on equity of the NDIS, it is vital that up-to-date data is made available to researchers via an enduring platform, rather than on an ad-hoc basis.

The NDIA currently provides some of their data for linkage with other administrative and research data sets into the Multi Agency Data Integration Project (MADIP) of the Australian Bureau of Statistics (ABS). However, there are gaps in this data. We recommend that a secure platform where researchers can access unit record detailed data on NDIS participants is developed and that more detailed NDIS data is provided to ABS for linkage into MADIP. This would provide a step change in researchers ability to produce the analysis needed to ensure an equitable and effective NDIS. This data should also include people who have applied to access the NDIS but who were not granted access, and people who have also left the Scheme.

Monitoring and regular reporting of inequalities between NDIS participants, people with disability without NDIS funded plans, and people with and without disability is essential.

Currently, the NDIA reports on outcomes for participants using the NDIS Outcomes Framework that is not fit for purpose, and lacks granularity and consistency in implementation. Tracking outcomes over time for different cohorts of participants is important for understanding whether the supports people are accessing are resulting in positive outcomes. We note here, as previously, the importance of ensuring approaches to analysis enable "like for like" comparisons so we can gain a better understanding of the causes of inequalities.

To date more broadly, there is no reporting on inequalities between NDIS participants and people without disability. Measuring and monitoring inequalities in key outcomes through linked data would provide insights into whether the NDIS is being effective in narrowing existing gaps in social and economic participation and health and wellbeing between people with and without disability. Further, monitoring inequalities between different cohorts of participants would help determine whether the scheme is operating in an equitable way and identify groups of participants for whom the Scheme is not working well.

The [Disability and Wellbeing Monitoring Framework](#) was developed by the CRE-DH. It draws on the expertise of people with lived experience of disability as well as existing frameworks and indicator sets. It provides a comprehensive structure for measuring and reporting inequalities between people with and without disability across 19 life domains and tracking changes over time. If NDIS data were linked to survey and administrative sets used to generate the indicators (e.g., Survey of Disability, Ageing and Carers) then it would be possible to compare outcomes for NDIS participants and people with disability who are not participants. However, as noted above, the NDIS data in MADIP is not fit for this purpose currently.

The Disability and Wellbeing Monitoring Framework [Baseline Report](#) presents indicator data for people aged 18 to 64 years and shows that, in most domains, outcomes for people with disability are less positive than for those without disability on health status, social and economic participation, and access to services. Among people with severe disability, inequalities are even more apparent. Future reporting against the Disability and Wellbeing Monitoring Framework indicators will analyse the effectiveness of current and future policies and programs against achieved outcomes for people with disability, including NDIS participants.

More broadly, regular reporting on inequalities in outcomes achieved by NDIS participants is required to improve transparency and help to rebuild and maintain trust in the NDIS.

People with disability and their families need accessible information on service provider outcomes to enhance choice and control.

Improving the quality, consistent measurement, analysis and reporting of service provider availability and outcomes is a crucial and currently missing component of NDIS reporting or monitoring.

It is currently challenging to monitor the availability and quality of local NDIS markets, service use and outcomes without knowing where care is provided and who is utilising what ([Gutierrez-Colosia et al., 2022](#); [Salvador-Carulla et al., 2022](#)). Addressing this gap in NDIA reporting and monitoring has the potential to support the agency in its market stewardship role. It would also assist in understanding geographical accessibility and allow comparisons on the effectiveness of local markets at population and service-system levels. This requires a standard approach to mapping local service delivery systems. CRE-DH Associate Investigator Salvador-Carulla and colleagues ([2022](#)) in their mapping of global mental health, dementia and disability systems, demonstrated that monitoring of effectiveness and efficiency of local markets required standard descriptions and analysis tools, preferably evidence-based in line

with international best practice ([Gutierrez-Colosia et al., 2022](#); [Salvador-Carulla et al., 2022](#)).

Provider-level outcome data is rarely available to service users and their families, limiting their ability to choose effective programs and avoid programs that are not. This concern was clearly illustrated in the research by Xu and Stancliffe's Ticket to Work ([2019](#)), the program that informed the planning and implementation of the NDIS School Leaver Employment Supports (SLES). While the NDIA publishes [aggregated SLES outcome data](#), participants and their families cannot easily find the information on which to base their choice of a SLES provider. Ideally, such data should be disaggregated by key service-user characteristics (e.g., disability type, support needs) to assist people with intellectual and developmental disability to make well-informed choices between programs. Conveying high quality outcome data in an easily-accessible, effective and clear way will assist school leavers, their families, and high school teachers to make optimal choices about providers.

We recommend:

10. Develop and adopt standard terminology, consistent approaches, and robust measures to monitor and report on the availability of services in local markets. Review of the NDIS Outcomes Framework should be informed by the [CRE-DH Disability and Wellbeing Monitoring Framework](#).
11. Develop and adopt standard terminology, consistent approaches, and robust measures to monitor and report on provider-level outcomes data.
12. Invest in a secure platform where qualified (Five Safes Framework) researchers can access unit record detailed data on NDIS participants. The NDIA should also transfer more detailed data to ABS for linkage into MADIP. This would enable inequities in outcomes and their causes between NDIS participants; people with disability without NDIS packages; and people without disability more broadly to be understood, monitored over time and reported.

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