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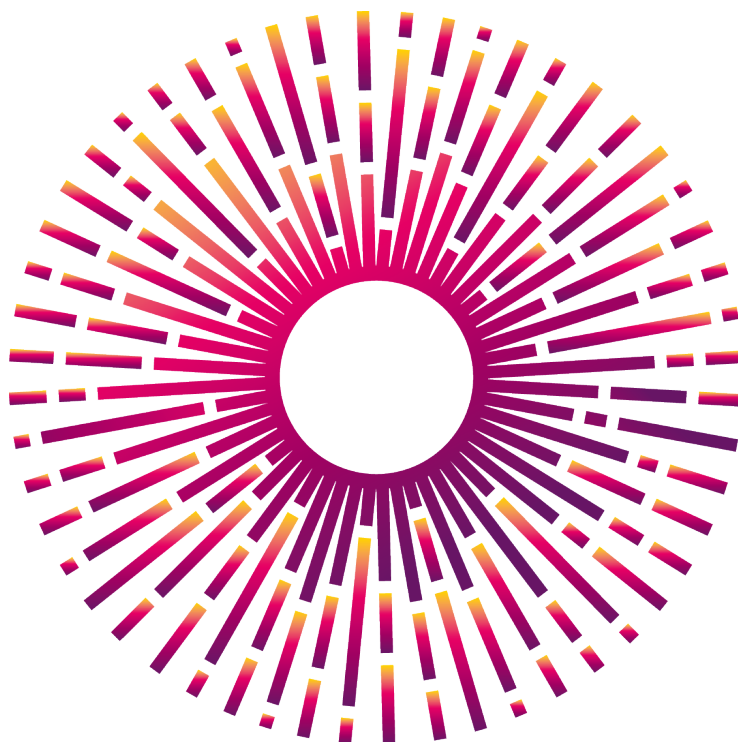


Discovering
what works
for families



NDS and NDIS Outcomes Frameworks Consultation

Submission from the Australian Institute of Family
Studies





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Glossary

Term	Description
AIFS	Australian Institute of Family Studies
DSS	Department of Social Services
GP	General Practitioner
LSAC	<i>Growing Up in Australia:</i> Longitudinal Study of Australian Children
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
TTM	<i>Ten to Men:</i> The Australian Longitudinal Study on Male Health



Overview

The Australian Institute of Family Studies (AIFS) welcomes the opportunity to provide feedback on the National Disability Strategy (NDS) and the National Disability Insurance Scheme (NDIS) Outcomes Frameworks Introductory Paper in the current round of public consultation (December 2020). Our responses are informed by the expertise of the researchers at AIFS and align with the work we undertake to improve the lives of families in Australia.

AIFS is the Australian Government's key family research body and advisor on family wellbeing. We create and communicate knowledge to accelerate positive outcomes for families – when families thrive, Australia thrives. Our work aims to increase understanding of the factors helping or hindering the wellbeing of Australia's families; thereby, building the evidence about 'what works for families' to inform policy and practice. We undertake and publish primary research across a broad range of issues affecting Australian families. This research encompasses quantitative, qualitative and mixed-methods approaches to data collection and analysis. We manage a number of major, large-scale longitudinal studies, and also regularly conduct policy and program evaluations. We use knowledge translation strategies to maximise the impact of this research for policy makers and practitioners.

As outlined in the Introductory Paper the NDS and NDIS Outcomes Frameworks will allow for tracking the effectiveness of NDS and NDIS through the progress of outcomes for people with disability. To achieve outcomes for people with disability, systematic and coordinated evidence-based decision making is required. Undertaking and translating high-quality and relevant research, program and service evaluation and outcomes monitoring is vital to generating such evidence; thereby, achieving the best possible outcomes for people with disability and their families in Australia through better service delivery and policies.

This submission includes responses to six of the eight consultation questions posed by the Department of Social Services (DSS), where consideration of the family context is most relevant to the outcomes for people with disability. Our responses draw on family-centred research evidence, including recent analysis of longitudinal data from *Growing Up in Australia: The Longitudinal Study of Australian Children (LSAC)* and other studies conducted by AIFS (Andalón & Swami, 2020), identifying family-centred indicators and measures across the domains of inclusive and accessible communities, economic security, health and wellbeing, life events, and personal and community support. The LSAC study is an ongoing, nationally representative study that has followed the lives of children and their families from all over Australia since 2004. With extensive information on children's physical, socio-emotional, cognitive and behavioural development and linked biomarkers, education, health and welfare data, the study has been a unique resource providing evidence for policy makers to identify opportunities for early intervention and prevention strategies. The study is a partnership between the Department of Social Services, the Australian Institute of Family Studies and the Australian Bureau of Statistics and is advised by a consortium of leading Australian academics.

This submission also outlines factors that could be considered to maximise the generation of useful information and the application of findings arising from the implementation of an Outcomes Frameworks approach.

This submission acknowledges that families come with a range of strengths and capabilities; however, there is broad recognition that families living with a member with disability may experience barriers such as increased levels of stigma, discrimination, financial stress, as well as transportation and physical barriers that hinder their full economic and social participation in society (Muir, Tudball & Robinson, 2008; World Health Organization, 2011). Our responses are



centred around the view that people with disability are also significant participants and contributors to families, and that understanding the family context is important to understanding a more complete range of experiences of people with disability and achieving outcomes across the domains identified in the Introductory Paper. Specifically, our responses suggest additions be made to the Outcomes Frameworks, such as:

1. Include outcomes, indicators and measures that acknowledge the person with disability as a participant and contributor to families.
2. Include indicators related to people with disability planning for parenthood and becoming parents.
3. Include indicators and measures that focus on family and carer health and wellbeing. For example, parent, carer and sibling physical and mental health, including stress and access to support services.
4. Draw on existing data sources that capture information against indicators of family wellbeing for people with disability, including national longitudinal studies LSAC and *Ten to Men: The Australian Longitudinal Study on Male Health (TTM)* and the Families in Australia surveys.
5. Ensure analysis and reporting against an Outcomes Framework and program evaluations are accompanied by a knowledge translation strategy to maximise the reach and potential to use findings from monitoring and evaluation.

Responses to the Outcomes Frameworks Introductory Paper Consultation

Response 1: What matters most to measure and report on as we seek to achieve inclusive and accessible communities for people with disability?

People with disabilities are both participants and contributors to biological and chosen families as children, partners, parents and siblings. Inclusion within families, and the family structure is an important consideration for measurement within this domain.

Australian research has shown that families including a child with disability are more likely to be headed by sole parents (31%) than families of children without disability (15%) (Cole, Crettenden, Roberts, & Wright, 2016). Other research has focused on divorce rates of parents caring for children with disability; however, the findings from international and Australian research has been mixed (Andalón & Swami, 2020; Clarke & McKay, 2008). In one study, women were found to be significantly more likely to have separated or divorced since they started caring for a person with disability who was not their partner (Edwards, 2009).

Within couples where a partner has a disability, research suggests an increased risk of separation (Brown, 2014; Clarke & McKay 2008; Li & Singleton, 2016). Findings from the LSAC study identified that one in five (20%) couples with one parent with disability in 2006 separated or divorced by 2016, compared to one in eight (13%) couples with no parent with disability did (Andalón & Swami, 2020).

Recent analysis of LSAC data identified that couples reported lower relationship satisfaction if a partner had a disability, and lower couple relationship quality for mothers living with a child with



disability (Andalón & Swami, 2020). These findings are supported by qualitative research that found that mothers and sole parents were likely to compromise their own needs in favour of those of other family members (Muir et al., 2008). Other research found that siblings of children with disability were more likely to experience their relationship as a carer or as a management relationship with their sibling with disability, rather than a sibling relationship (Meltzer, 2017).

Family and carer relationships are listed as an example indicator in the Introductory Paper. Based on the research outlined above, we recommend that in order to achieve inclusive and accessible communities for people with disability, the Outcomes Frameworks include indicators on family and carer relationships, including:

- divorce rates, family structure
- quality/satisfaction of couple relationships
- quality/satisfaction of sibling relationships
- quality/satisfaction of parent/child relationships.

The LSAC study collects data against these indicators for Australian families, including families with a member with disability. The TTM study also includes indicators on relationships between Australian boys, adolescents and adult men with other family members, relatives and friends.

Response 2: What is most important to measure and report on as we seek to achieve economic security for people with disability?

The economic security of children with disability, and their future prospects, are impacted by the economic circumstances of their families. Research indicates that parents of children with disability experience worse economic outcomes, including experiencing financial hardship (Maguire, 2012) and being less likely to be employed (Maguire, 2012; Qu, Edwards, & Gray, 2012). More recently, research with Australian families found that families with a member with disability experience poorer economic outcomes (Andalón & Swami, 2020). Parental weekly income was lower among families who had a member with disability, especially when it was one or both parents with disability (Andalón & Swami, 2020). One in four families with a member with disability were jobless, compared to one in 10 with no parent/s or child/ren with disability (Andalón & Swami, 2020).

In addition to the outcomes and indicators listed in the Introductory Paper, indicators could be included at household and/or family and carer level for income, employment, economic security and financial stress. The LSAC study captures indicators for family employment status including family job status, and weekly parental income for both parents with disability and children with disability. Similarly, the TTM survey includes indicators on household income and composition and home ownership, which can be disaggregated by disability status.

Response 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 of people with disability will be impacted by the wellbeing of their families and carers. The evidence outlined below supports the inclusion of carer and family physical and mental health, as well as health and support service utilisation indicators in the



Outcomes Frameworks. Indicators could be included to capture family and carer stress, mental health and access to appropriate mental health and support services. A number of these indicators are collected as part of LSAC. Examples of indicators for consideration within the Health and Wellbeing domain of the Outcomes Frameworks include:

- parent or carer use of health services (including mental health services, GP, social work, counsellor)
- sibling of person with disability use of health and support services (including counselling, peer support, parental resources)
- unmet mental health care needs of parents or carers
- access to emotional/informational support, tangible support and positive social interaction for family members or carers especially mothers
- access to social and peer support for family members
- timeliness of access to support
- parent or carer mental health indicators (psychological stress, anxiety, depression, suicidality, attempted suicide)
- sibling mental health indicators
- physical health indicators for carers and family members.

Mental and physical health of families of people with disability

Research with Australian families found that both mothers and fathers of a child or children with disability report higher psychological stress compared to parents without a child with disability (Andalón & Swami, 2020; Dillon-Wallace & McDonagh, 2014). Studies of mothers of children with disability in Victoria found higher rates of clinical depression and anxiety than the rates reported for women in the general population, as well as higher rates of suicidality (22% vs 3%) and attempted suicide (4% vs 0.5%) (Gilson, Davis et al., 2018; Gilson, Johnson et al., 2018). These findings are supported by evidence from health care professionals who identify that mental health difficulties are very common in the families with disability that they support (Gilson, Johnson et al., 2018). Children who have one or both parents with disability also report higher levels of depression and anxiety or other mental health problems, compared to children with parents without disability (Andalón & Swami, 2020; Sibling Australia, 2017).

Mothers of a child or children with disability also report poorer physical health compared to mothers with children without disability, although the self-reported health of fathers living with a partner or child with disability did not differ to that of fathers not living with a family member with disability (Andalón & Swami, 2020). Other Australian research suggests that parents living with children with disabilities generally experience poorer physical health outcomes than parents living with no children with disability (Dillon-Wallace & McDonough, 2014; Seymour et al., 2017), as do children with a parent with disability (Andalón & Swami, 2020).

Social support for parents

Social support is essential for physical and mental health and wellbeing (Uchino, 2006). Mothers of children with disability reported lower access to emotional, tangible and affectionate support and positive social interaction compared to those without a child with disability (Andalón & Swami, 2020). Similarly, mothers with a partner with disability reported lower levels of access to emotional support and positive social interaction compared to mothers with a partner without disability (Andalón & Swami, 2020).



Access to and use of services for families of people with disability

Families with a member with disability report greater use of support services at a family level and child level, including counselling, disability services and adult mental health services compared to families without a member with disability (Andalón & Swami, 2020). Research from Victoria suggests that mothers of children with disability (aged 0–25 years) most commonly use mental health services, followed by GP and social and counsellor services (Gilson, Davis et al., 2018; Gilson, Johnson et al., 2018). Families living with a member with disability used parenting and relationships education, family support groups and phone or internet services more often than families not living with a member with disability; however, these support services were only used by less than one in 10 families with disability (Andalón & Swami, 2020).

Additional evidence from Australian studies has shown that there are unmet mental health needs amongst parents. Mothers and fathers were less likely to get the support they needed compared to those without a family member with disability (Andalón & Swami, 2020). Also, less than half of siblings and parents who are carers for a person with disability had accessed support services for themselves, with only one-third feeling that it had met their needs fully (Siblings Australia, 2017).

Response 6: What is most important to measure and report on as we seek to achieve personal and community support outcomes for people with disability?

For people with disability who are parents or who are planning to become parents, evidence shows that social conditions and beliefs can have a negative impact on parenting capacity (McConnell, 2008). Factors including a fear of judgement (Collings, Grace, & Llewellyn, 2017), a lack of accessible information, poor engagement by services, lack of cross-agency collaboration (MacIntyre, Stewart & McGregor, 2019) and a need for a more disability-aware and skilled workforce (Slayter & Jensen, 2019) can be barriers to parents with disability seeking parenting support services. Both strengths-based and relationship-based approaches to supporting parents with disability are valued, and a range of principles to providing support and services to parents with intellectual disability have been documented (Collings & Spencer, 2020).

In light of the evidence, the Outcomes Frameworks could consider indicators of access to parenting resources and support for parents with disability, including peer support and networks, as well as barriers to accessing parenting support resources, including stigma or judgement around parenting (Collings & Spencer, 2020). Including indicators to reflect the support needs for both the person with disability and their families or carers at times of transition are particularly pertinent (Brown, Higgins, & MacArthur, 2020). Data on the level of support accessed by parents and families¹ with a member with disability is currently collected by AIFS in LSAC.

¹ Support needs for parents, families and carers are discussed in more detail in Response 3.



Response 7: 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?

Given the potential range of data sources that will contribute to the Outcomes Framework reporting, a combination of biannual (as proposed in the NDS Strategy Position Paper, DSS (2020)), annual and quarterly reports may be useful to a range of audiences.

For example, depending on the final data sources, making a range of 'dashboard' type summaries available to people with disability, peak bodies and other organisations, for selected indicators would be valuable for ongoing accountability and opportunity for service improvements. The NDS Strategy Position Paper (DSS, 2020) suggests that the National Disability Data Asset will be a tool to enable timely access to monitoring data for consumers.

In order to maximise the dissemination and encourage the use of findings from monitoring and evaluation activities against the NDS, we suggest that any plan for reporting outcomes and policy and program evaluation findings be accompanied by a Knowledge Translation strategy. A Knowledge Translation strategy could include a range of activities that facilitate the use of evidence for impact, including:

- the development of policy briefs, practice resources, and easy-read resources
- plans to engage with policy makers, practitioners, consumers and families to use findings
- assistance for organisations and practitioners to utilise evidence in service design and improvements.

Response 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?

Measuring family and carer outcomes

The Introductory Paper describes both population-level outcomes and person-centred outcomes. While we support this approach and acknowledge the role of the Strategy and Outcomes Frameworks as the primary mechanism for Australia to implement its obligations under the United Nations Convention on the Rights of Persons with Disability, in light of the evidence presented above relating to families and carers of people with disability, consideration could also be given to a family-, carer- or household-level of outcomes as an additional layer in the Outcomes Frameworks.

Equity and diversity

Considerations for issues of equity, cultural differences, the diversity of people with disability, and family and support structures need to be taken into account in the collection, reporting and interpretation of information gathered in any Outcomes Frameworks implementation.



Measuring outcomes for people with disability in key areas and using the findings to inform resource allocation and evidence-based decision making is an important addition to the new Strategy (DSS, 2020). While we agree that it is necessary to have an overarching outcomes framework, there is a risk of unintended consequences of reporting against high-level and universal indicators in a diverse population. There is a risk that the most vulnerable populations will not be sufficiently represented if additional effort is not made to tailor monitoring and outcomes data collection and interpretation.

Capacity building for disability organisations

In order to maximise the reach and utility of outcomes measurement and evaluation of initiatives under the Strategy, it will likely be necessary to build the capacity of service providers and other disability organisations to contribute to monitoring and evaluation processes. This will provide an opportunity for meaningful indicators and measures to be developed with local or population specific relevance.

To build such capacity and support for organisations to develop, collect and interpret their own monitoring and evaluation reports, dedicated resourcing would be required, with particular attention paid to the medium and smaller organisations who may not have previously engaged in this kind of activity (Stewart, 2014).

Participation of people with disability in outcomes measurement and evaluation

Recent published research published articulates the importance of ensuring that people with disability are also enabled to participate in the development of policies and services that affect their lives (Frawley, 2020), including the interpretation of outcome measurement and program evaluation findings. Participation in outcomes measurement builds on approaches already taken to ensure that people with disabilities are able to participate in the development of legislation, policy and practice in accordance with the United Nations Convention on the Rights of Persons with Disabilities.

Final comments

This document is a submission to the NDS and NDIS Outcomes Frameworks consultation. Our responses are centred around the view that people with disability are significant participants and contributors to families, and that understanding the family context is important to understanding people with disability and achieving outcomes across the domains identified in the Introductory Paper. Our responses are informed by family-centred research evidence and the expertise of AIFS researchers. We have identified a number of family-centred indicators and measures, based on the evidence, that could be adopted in the Outcomes Frameworks. We have also outlined factors that could be considered to maximise the generation of useful information and the application of findings arising from the implementation of an Outcomes Frameworks approach.

References

- Andalón, M., & Swami, N. (2020). *Understanding families living with a member with disability*. Melbourne: Australian Institute of Family Studies.
- Brown, L. (2014). *Diversity, participation and people with disability*. Canberra: Institute for Governance and Policy Analysis, University of Canberra. Retrieved from www.governanceinstitute.edu.au/magma/media/upload/ckeditor/files/Diversity%20and%20participation.pdf



- Brown, M., Higgins, A., & MacArthur, J. (2020). Transition from child to adult health services: A qualitative study of the views and experiences of families of young adults with intellectual disabilities. *Journal of Clinical Nursing*, 29, 195–207. doi.org/10.1111/jocn.15077
- Clarke, H., & McKay, S. (2008). *Exploring disability, family formation and break-up: Reviewing the evidence*. London: Department for Work and Pensions. Retrieved from lx.iriss.org.uk/content/exploring-disability-family-formation-and-break-reviewing-evidence
- Cole, L., Crettenden, A., Roberts, R., & Wright, A. (2016). The experience of sole mothers balancing paid work with care for a child with a disability. *Australian Journal of Social Issues*, 51(3), 317–339.
- Collings, S., Grace, R., & Llewellyn, G. (2017). The role of formal support in the lives of children of mothers with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30(3), 492–500.
- Collings, S., & Spencer, M. (2020). *Practices that support parenting by parents with intellectual disability*. Melbourne: Australian Institute of Family Studies. Retrieved from aifs.gov.au/cfca/2020/09/30/practices-support-parenting-parents-intellectual-disability
- Department of Social Services (DSS). (2020). *National Disability Strategy Position Paper*. Canberra: DSS. Retrieved from engage.dss.gov.au/nds-stage2-consultation/national-disability-strategy-position-paper
- Dillon-Wallace, J. A., & McDonagh, S. H. (2014). How stable is the well-being of Australian mothers who care for young children with special health care needs? *Journal of Child and Family Studies*, 23, 1215–1226.
- Edwards, B. (2009). Caring for families caring for a person with a disability. *Family Relationships Quarterly*, 11, 3–9. Retrieved from aifs.gov.au/cfca/publications/family-relationships-quarterly-no-11
- Frawley, P. (2020). *Lived experience of people with disabilities: Shaping policy and practice*. Melbourne: Australian Institute of Family Studies. Retrieved from aifs.gov.au/cfca/2020/10/13/lived-experience-people-disabilities-shaping-policy-and-practice
- Gilson, K-M., Davis, E., Johnson, S., Gains, J., Reddihough, D., & Williams, K. (2018). Mental health care needs and preferences for mothers of children with a disability. *Child: Care, Health and Development*, 44, 384–391.
- Gilson, K. M., Johnson, S., Davis, E., Brunton, S., Swift, E., Reddihough, D., & Williams, K. (2018). Supporting the mental health of mothers of children with a disability: Health professional perceptions of need, role, and challenges. *Child: Care, Health and Development*, 44(5), 721–729.
- Li, L., & Singleton, P. (2016). The dynamic effect of disability on marriage: Evidence from the Social Security Disability Insurance Program. New York: Syracuse University. Retrieved from www.maxwell.syr.edu/uploadedFiles/cpr/publications/working_papers2/wp190.pdf
- MacIntyre, G., Stewart, A., & McGregor, S. (2019). The double-edged sword of vulnerability: Explaining the persistent challenges for practitioners in supporting parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32(6), 1523–1534.
- Maguire, B. (2012). Families with a child with disability: Joblessness, financial hardship and social support. In Australian Institute of Family Studies, *The Longitudinal Study of Australian Children: Annual statistical report 2011*. Melbourne: Australian Institute of Family Studies.
- McConnell, D. (2008). Parents labelled with intellectual disability: Position of the IASSID SIRD on parents and parenting with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 296–307.
- Meltzer, A. (2017). 'I couldn't just entirely be her sister': The relational and social policy implications of care between young adult siblings with and without disabilities. *Journal of Youth Studies*, 20(8), 1013–1027.
- Muir, K., Tudball, J., & Robinson, S. (2008). *Family resilience where families have a child (0–8 years) with disability: Final report* (SPRC Report 10/08). Report prepared for the Disability Policy and Research Working Group (DPRWG), Commonwealth State/Territory Disability Agreement Australian Government, Social Policy Research Centre, UNSW, June 2007.
- Qu, L., Edwards, B., & Gray, M. (2012). *Ageing parent carers of people with a disability*. Melbourne: Australian Institute of Family Studies.
- Seymour, M., Giallo, R., & Wood, C. E. (2017). The psychological and physical health of fathers of children with Autism Spectrum Disorder compared to fathers of children with long-term disabilities and fathers of children without disabilities. *Research in developmental disabilities*, 69, 8–17.
- Siblings Australia (2017). *Mapping Project: Support for siblings of children and adults with disability, final report*. Adelaide SA: Siblings Australia. Retrieved from siblingsaustralia.org.au/wp-content/uploads/2018/01/FINAL-Siblings-ILC-Mapping-Project-Report.pdf
- Slyter, E. M., & Jensen, J. (2019). Parents with intellectual disabilities in the child protection system. *Children and Youth Services Review*, 98, 297–304.
- Stewart, J. (2014). *Developing a culture of evaluation and research* (CFCA Paper No. 28). Melbourne: Australian Institute of Family Studies. Retrieved from aifs.gov.au/cfca/publications/developing-culture-evaluation-and-research
- Uchino, B. N. (2006). Social support and health: a review of physiological processes potentially underlying

links to disease outcomes. *Journal of Behavioral Medicine*, 29(4), 377–387.
World Health Organization. (2011). *World report on disability 2011*. Geneva: World Health Organization.

