

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

Siblings Australia welcomes the opportunity to contribute to the Outcomes Frameworks Introductory paper. It also welcomes the introduction of a Framework which will track the effectiveness of the National Disability Strategy and the NDIS through agreed national outcomes, indicators and measures.

We would like to begin by stating our position that family is central and that whole-of-family support and capacity building is vital to improving outcomes for people with disability over a lifetime. We would also assert that although these concepts are widely understood and written into both legislation and policy, they are not evident on the ground, on an operational level. Our strong belief is that this is due to a lack of quality reporting mechanisms that give imperative to transfer these principles into practice. This is what we hope to influence through this submission.

Families in disability policy

Both the National Disability Strategy and the NDIS include a commitment to ensuring PWD and their families get the support they need. For example, in relation to the NDIA Act, one of the aims listed under the 'purpose of the NDIS' is to:

- facilitate the development of a nationally consistent approach that provides support to eligible Australians, ensuring that people with disability **and their families** (emphasis added) get the support they need when they need it.

The General Principles of the Act include:

- the role of **families**, carers and other significant persons in the lives of people with disability is to be acknowledged and respected (section 4(12));
- the supportive **relationships**, friendships and connections with others of people with disability should be recognised (section 5(e)).

Also, in response to the Tune Review, which emphasised the need to build capacity in families, the government has reiterated that, 'The NDIA has an important role to assist **families** and carers of people with disability (PWD) to identify, and in turn engage with or strengthen the **natural relationships** that exist within their home and community.'

However, current policy does not translate into clear outcomes in relation to families. The focus is on parents and carers, and often overlooks the important contribution and needs of siblings.

Why families?

Children live and thrive in the context of their families. For all children, but especially children with disability, the whole family is an essential support system. And for the family to be the best support system it can be, it needs to access support tailored to the whole family, not just the person with

disability and parents. Siblings will likely have the longest relationship of anyone with a person with disability. If that relationship can be strengthened and nurtured in the early years, it is more likely to be an enduring one. Even if the sibling does not provide a direct caregiving role, the relationship itself can bring enormous benefit to both siblings. If siblings are overlooked, they are more likely to move away from the family leading to greater vulnerability for the person with disability.

Siblings Australia offers the following feedback regarding the Outcomes Framework draft and how the domains relate to families and their contributions. We also highlight where references to families (including siblings) have been overlooked or excluded and provide some recommendations for consideration.

Domain: Inclusive and accessible communities

Supportive relationships have been identified within this domain with 'family/carer relationships' as one of the key indicators. We agree that this is an important indicator to include.

Full social inclusion within communities is enabled, enriched and enhanced with the direct involvement of the whole family, including siblings. The natural relationship between siblings and PWD can facilitate access and meaningful participation within the community, and this can continue across the whole lifespan.

Recommendation: The indicator 'family/carer relationships' take a whole family perspective and measure both the existence and quality of sibling relationships.

Domain: Economic security

This domain focuses on outcomes to enable PWD and their families to have choice and control over their lives and an ability to plan for the future. We agree strongly that this is a key outcome that should be measured.

It is undeniable that strong family functioning and security is vital to achieving this outcome. Therefore, indicators that measure the economic security of families of PWD should not be overlooked.

Siblings should be considered along with parents and the person with disability. They can assist with planning for the future if they have the capacity to navigate the disability system and can develop knowledge and skills to support their brother or sister, such as supported decision-making, guardianship, financial management etc. At the same time, their own economic security can be compromised if they are needed to take over more of a 'hands-on' role in advocating for their brother/sister to ensure they access what they need for a 'good life'.

Recommendation: Indicators include reference to family economic security.

Domain: Health and wellbeing

The family role within this domain is unquestionable. The health and wellbeing of the whole family and carers, along with the strength of family relationships, is crucial to the long-term health and wellbeing of PWD. In other Domains, such as Economic Security and Personal and Community

Support, the main outcome includes the words 'PWD, families and carers' specifically, but not in this domain.

In addition, the quality of every sub-outcome relies heavily on family input, which in many cases incorporates sibling involvement – whether it be contributing to the mental/emotional/social health of a brother/sister with disability, accompanying them to health appointments or assisting them to access the best possible professionals, siblings contribute to strong outcomes in this area.

A good measure of this outcome would be whether PWD have family members who can support them to maximise their health and access health services.

Again, measuring the involvement of siblings in the lives of PWD, and the quality of those relationships, would be sound indicators of health and wellbeing outcomes.

Recommendation: 1. This domain include families and carers in the main outcome. For consistency, the indicator 'carer health and wellbeing' be changed to 'family health and wellbeing', with clear and relevant measures aligned to whole family outcomes, not just carers. 2. Include measures related to the involvement of siblings in the lives of PWD over a lifetime and the quality of those relationships.

Domain: Rights, protection, justice and legislation

When it comes to the protection and exercising of rights, families are key players. They intrinsically take on an important role within this domain, often forming the first line of defence when PWD face discrimination or inequity. This natural relationship is a powerful protective force and should be recognised as such within authorised frameworks and documents. Again, support for the sibling relationship in the early years will add to the strength and longevity of the relationship. Providing information and resources to siblings will build their capacity to be strong advocates for their brother/sister.

Recommendation: Include indicators that measure both the quality of the relationship but also the capacity of siblings to advocate for and support PWD.

Domain: Learning and skills

Participation in quality education, again, often rests on family involvement and input. Modification to learning programs and environments, successful transition to further education opportunities, monitoring learning goals and outcomes are all areas that are enhanced through strong family involvement and input.

Recommendation: Include a sub-outcome and indicator that capture family involvement in PWD reaching their full learning potential.

Domain: Personal and community support

Families are clearly recognised within this domain, through the words, 'people with disability, their families and carers have access to a range of well-coordinated and effective services and supports that are appropriate for their needs'.

Recommendation: 1. Include appropriate and relevant indicators that capture the experience of all family members.

2. Develop relevant indicators to measure 'my family and carers feel that their roles are acknowledged by providers'.

Conclusion

Our overriding argument and message is that **family involvement** is a crucial indicator within every domain. We are encouraged by the presence of some family inclusive language within domains, sub-outcomes, and example indicators but this needs to be more consistent and be intrinsically linked throughout the framework.

It is universally known and recognised that a whole family, family-centred approach forms an important guiding principle in the support of people with disability. This is clear with regard to parents/carers, but quality sibling relationships can make a huge difference in terms of social inclusion, wellbeing and safety of PWD over their lifetime. Now is the time to incorporate this truth into well-defined outcomes measures to enable healthier relationships and a higher quality of support for PWD. Such measures would ensure the proper implementation of the NDIA Act (as above).

There may need to be some mapping carried out on family relationships and the nature of those relationships. It would also be beneficial to explore some of the barriers and enhancers to those relationships. Siblings Australia would be well placed to contribute to that work.

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