

# **NDS and NDIS Outcomes Frameworks Public Consultations**

**Spinal Cord Injuries Australia Policy  
and Advocacy Team Submission**

**December 2020**

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**National Disability Strategy Governance and Engagement Section**  
**Department of Social Services**  
Via email to [disabilityreform@dss.gov.au](mailto:disabilityreform@dss.gov.au)

## **Introduction**

Spinal Cord Injuries Australia (SCIA) welcomes the opportunity to offer a submission to the Department of Social Services' (DSS) public consultations on the Draft Outcomes Frameworks for the National Disability Strategy (NDS) and National Disability Insurance Scheme (NDIS). SCIA strongly supports adopting a consistent national approach to measuring, monitoring and regularly reporting on the outcomes of the NDS and NDIS. Similarly, SCIA endorses the establishment of appropriate mechanisms for effective accountability and transparency.

## **About Spinal Cord Injuries Australia**

SCIA is a for-purpose organisation working for people living with spinal cord injury (SCI) and other physical disabilities. SCIA was founded by people with SCI over fifty years ago; people with disability make up over 25% of our staff, and the majority of our Board live with SCI. SCIA is a national, member-based organisation that serves 2,500 members made up of people living with disability, their family, carers, researchers, and other professionals in the sector.

SCIA's Policy and Advocacy Team provides individual and systemic advocacy, and supports self-advocacy, with the aim of ensuring that people living with SCI and other disabilities do not face barriers in exercising their independence and realising their human rights. The team strives to achieve inclusivity and change for people with disability, their family members or carers.

## Recommendations

### **Recommendations: Inclusive and accessible communities**

- *Replace 'well-designed' with 'universally-designed' in the outcome statement.*
- *Include the word 'reliably' and/or 'always' to the sub-outcome 'I can access' to read 'I can reliably and/or always access'.*
- *Re-phrase the sub-outcome to read 'I can access social, civic and cultural events'.*
- *Include the sub-outcome: 'I have access and knowledge of relevant communication and information networks'.*
- *Re-phrase the final sub-outcome to read 'I have supportive relationships with family, friends, carers, support workers and health practitioners and community members'.*
- *Include representation of people with disability in the media as an example indicator.*
- *Include an additional outcome under the domain that acknowledges the significance of accessibility and inclusivity in communications, rather than just a separate sub-outcome.*

### **Recommendations: Economic security**

- *Add the sub-outcome: 'I have appropriate support and information to find relevant job opportunities and maintain long-term employment'.*
- *Add the sub-outcome: 'As a family member or carer, I am aware of available economic supports, including the carer's pension, that will ensure our financial stability'.*
- *Include the following example indicators: 'utilisation of disability-specific employment services'; 'employer knowledge of disability supports in the workplace and staff awareness training'.*
- *In the example indicator, 'Access to housing options that are suitable, affordable and provide secure tender', the following should be added: 'across all housing categories including private and social housing as well as Specialist Disability Accommodation for eligible NDIS participants'.*
- *The following example indicator should be added: 'Delays in discharge from hospital due to unavailability of suitable housing options'.*

### **Recommendations: Health and wellbeing**

- *Re-phrase the sub-outcome to read 'I can find, access and interact with health professionals who understand my needs'.*
- *Re-phrase the sub-outcome to read 'My GP, hospital and other health care providers are accessible and understand my disability needs'.*
- *Include 'Access to peer support and mentoring programs' as an example indicator.*

### **Recommendations: Rights, protection, justice and legislation**

- *Include the sub-outcome: 'I have access to legal and non-legal advocacy services'.*
- *Include the sub-outcome: 'I know where to find information and assistance when making a complaint'.*

### **Recommendations: Learning and skills**

- *Include the sub-outcome: 'I have access to educational materials that I can understand'.*
- *Re-phrase the sub-outcome to read: 'I can get to educational institutions easily and have access to all available facilities there'.*

**Recommendations: Personal and community support**

- *Include access to AT and equipment within the outcome of the domain, to read: '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, and this includes universal access to assistive technology and equipment'.*
- *Include the example indicator: 'Market concentration of NDIS and non-NDIS disability support service providers'.*
- *Either specifically reference client satisfaction with long-term, stable access to the same service provider OR re-phrase the sub-outcome to read: 'The services and support persons I access are well-coordinated and allow me to develop long-term relationships of trust'.*

**Recommendations: Other**

- *A shared person-centred sub-outcome directly relating to families and carers should be added to the following domains: Economic security, Personal and community support.*
- *Include a sub-outcome across all domains that relates to the community's attitudes toward people with disability and their understanding of their role in promoting inclusivity within the community and ensure that a shared indicator can be implemented to assess community's attitudes.*
- *Include a specific sub-outcome that applies to all domains measuring engagement of people with disability and their families and carers in the monitoring of the outcomes frameworks.*

The following submission reflects SCIA's commitment to the vision and successful, on-going implementation of the new NDS and NDIS. It also provides feedback on DSS's proposed domains, outcomes, sub-outcomes and example indicators.

### **Inclusive and accessible communities**

For people with spinal and neurological conditions, inclusivity and accessibility are crucial to removing barriers in day-to-day life. The current wording of the outcome is appropriate; however, we recommend replacing the term 'well-designed' with 'universally-designed'. This aligns with the proposed guiding principle for the NDS - 'Design universally';<sup>1</sup> and accords with the United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD).<sup>2</sup>

#### **Recommendation**

*Replace 'well-designed' with 'universally-designed' in the outcome statement.*

SCIA appreciates the inclusion of person-centred outcomes in the frameworks as it reflects the importance of engaging people with disability in assessment of the progress of the NDS and NDIS. There are some alterations that could be made to these sub-outcomes to better reflect the needs and experiences of people with physical disability accessing the community. In the sub-outcome, 'I can access', it would be appropriate to add either 'reliably' and/or 'always'. Following consultation with SCIA members on community access, it seems that even in metropolitan areas where measures have been taken to increase physical accessibility, often people still encounter barriers. For example, several buildings have constructed wheelchair lifts, rather than ramps, to increase accessibility, but SCIA members have routinely found that these lifts are out of order. Similarly, many people who use disabled toilets have found them inaccessible as proprietors often use them as storage areas. In light of these experiences, it is appropriate to acknowledge that while measures may have been taken to increase physical accessibility, example indicators should take account of not only the number of measures implemented, but rather their actual efficacy in improving access on a regular basis.

#### **Recommendation**

*Include the word 'reliably' and/or 'always' to the sub-outcome 'I can access' to read 'I can reliably and/or always access'.*

Within the domain generally, reference is often made to access and participation in social and cultural events. Participation in civic events, including public hearings, rallies, ceremonies, decisions and community-sponsored protests, is also an important element that reflects inclusion with society and acknowledges the political agency of people with disability. As such, SCIA recommends including the word 'civic' to the sub-outcome 'I can access social and cultural events'.

#### **Recommendation**

*Re-phrase the sub-outcome to read 'I can access social, civic and cultural events'.*

SCIA also endorses the inclusion of accessibility to communication and information networks, as it acknowledges the specific needs of those with communications disabilities and for those who may face other barriers due to a lack of computer literacy or referral pathways. It would also be useful, in

<sup>1</sup> DSS, 'National Disability Strategy: Position Paper', July 2020, p. 7.

<sup>2</sup> See Article 4 of the *Convention on the Rights of Persons with Disabilities*.

the sub-outcome, 'I have access to communication and information networks', to add that all people with disability are made aware of available and relevant communication and information networks that could impact their access to services and programs. Particularly for people with newly acquired injuries, knowing where to get relevant information after discharge from hospital can dramatically affect their understanding of their rights, housing options, employment, eligibility for the NDIS and other programs. Additionally, for those with limited computer literacy finding relevant information may be challenging. As such, SCIA makes the following recommendation:

**Recommendation**

*Re-phrase the sub-outcome to read 'I have access and knowledge of relevant communication and information networks'.*

SCIA welcomes the inclusion of recognising the significance of supportive relationships for people with disability within the sub-outcomes. Though it would be useful to distinguish different types of relationships people have in recognising peoples' different roles. For example, it is helpful to specify different relationships with family, friends, carers, support workers and health practitioners, and community members. As such, the following could be added to the sub-outcome:

**Recommendation**

*Re-phrase the final sub-outcome to read 'I have supportive relationships with family, friends, carers, support workers and health practitioners and community members'.*

In relation to the list of example indicators, it would be helpful to include representation of people with disability in the media. Based on consultation with people with spinal and neurological conditions and their family members, many felt that media representation directly reflected their sense of inclusiveness in the community. Broadcast of the Paralympics was cited by many as a significant development in disability being normalised in the community.

**Recommendation**

*Include representation of people with disability in the media as an example indicator.*

Finally, recognising the specific needs of people with communications disabilities is a very significant development in understanding accessibility. While it is useful to distinguish between physical and communications accessibility in the sub-outcomes, establishing greater awareness of the two could be better effected by including two separate outcomes under the domain heading.

**Recommendation**

*Include an additional outcome under the domain that acknowledges the significance of accessibility and inclusivity in communications, rather than just a separate sub-outcome.*

## **Economic security**

Recognising the vital role of economic security in providing financial stability, independence and affirming a sense of self-worth is rightly set out in the second domain. SCIA does have a few recommendations to better substantiate the outcomes and measurement indicators in this domain.

In relation to the sub-outcomes, it is again important to emphasise that people with disability and their families and carers have access to information on employment opportunities and relevant housing options. The current system of available supports and information can be confusing to

navigate and understand and it would be useful to measure people's understanding or awareness of available supports they may be eligible for in searching for a job and supports for employers. This is particularly important for people when accessing Disability Employment Services. This includes awareness of available economic supports for families and carers. This is supported by evidence from family members of people with spinal and neurological conditions who have recounted situations in which they were unaware of their eligibility for the carers pension and were not financially secure for long periods as a result. This should also be accounted for in the example indicators. SCIA makes the following recommendations:

**Recommendations**

*Add the sub-outcome: 'I have appropriate support and information to find relevant job opportunities and maintain long-term employment'.*

*Add the sub-outcome: 'As a family member or carer, I am aware of available economic supports, including the carer's pension, that will ensure our financial stability'.*

*Include the following example indicators: 'utilisation of disability-specific employment services'; 'employer knowledge of disability supports in the workplace and staff awareness training'.*

Finding and choosing suitable, long-term housing is another vital outcome for all people with disability. This is a pressing issue for people with newly acquired injuries, as finding appropriate accommodation following discharge from hospital can present major delays. In order to measure the progress toward achieving this outcome SCIA recommends clarifying and adding further example indicators to better understand the range of housing options available to people with disability:

**Recommendations**

*In the example indicator, 'Access to housing options that are suitable, affordable and provide secure tender', the following should be added: 'across all housing categories including private and social housing as well as Specialist Disability Accommodation for eligible NDIS participants'.*

*The following example indicator should be added: 'Delays in discharge from hospital due to unavailability of suitable housing options'.*

**Health and wellbeing**

This domain is especially relevant in light of recent research into the disparity in health outcomes for people with disability.<sup>3</sup> There are just a few amendments to the draft that could provide greater insight into these outcomes. Again, accessibility to health information and referral pathways to appropriate specialists can impact health outcomes and this should be reflected in the sub-outcomes. For people living in rural and remote areas this is particularly important to ensure that they have reasonable access to suitable specialists, without incurring significant personal expense to travel to metropolitan areas. Further, hospital staff, community health providers and specialists should have at least a basic understanding of patients' disability needs and how this may impact treatment for non-disability related health issues. Additionally, for those living in aged care facilities it is important that not only their health needs met, but that they have access to advice and treatment from nursing staff with disability expertise. Further, another important support that can impact health outcomes and provide

<sup>3</sup> See for example Australian Institute of Health and Welfare, 'Mortality patterns among people using disability support services: 1 July 2013 to 30 June 2018 - Summary', September 2020.

psychosocial support for people with disability throughout their life is peer support and mentoring. Accordingly, SCIA recommends the following:

**Recommendations**

*Re-phrase the sub-outcome to read 'I can find, access and interact with health professionals who understand my needs'.*

*Re-phrase the sub-outcome to read 'My GP, hospital and other health care providers are accessible and understand my disability needs'.*

*Include 'Access to peer support and mentoring programs' as an example indicator.*

**Rights, protection, justice and legislation**

When measuring whether rights, protection and legislation outcomes for people with disability have been met, access to advocacy services and affordable legal support is a useful enabler. Additionally, people with disability and their families and carers need to be aware of the available supports and platforms through which to assert their rights. For example, depending on the matter, people should be aware of the right to make a complaint to the Australian Human Rights Commission (AHRC) or to the NDIS Quality and Safeguards Commission. The following recommendations reflect this need for advocacy and accessible information:

**Recommendations**

*Include the sub-outcome: 'I have access to legal and non-legal advocacy services'.*

*Include the sub-outcome: 'I know where to find information and assistance when making a complaint'.*

**Learning and skills**

Physical and communications accessibility is also a major factor that ensures there are no barriers for people with disability when accessing education. SCIA members have reported that without appropriate accessibility measures being implemented by their schools and universities, which included the construction of ramps and adoption of new safety procedures, they would have been barred from attending mainstream educational institutions. Additionally, it is important to integrate communications accessibility measures within education institutions, in the distribution of teaching materials, which may be facilitated by assistive technology. This domain should further emphasise the significance of accessibility:

**Recommendation**

*Include the sub-outcome: 'I have access to educational materials that I can understand'.*

*Re-phrase the sub-outcome to read: 'I can get to educational institutions easily and have access to all available facilities there'.*

**Personal and community supports**

For people with spinal and neurological conditions, access to assistive technology and equipment is a "critical survival matter".<sup>4</sup> This domain should explicitly refer to access to assistive technology (AT) and

<sup>4</sup> Quote from a survey conducted with SCIA members between 30 September to 22 October 2020.



equipment, especially as this reflects the government’s responsibilities under the UNCRPD.<sup>5</sup> Additionally, universal, timely access to AT and equipment involves choice and control. Users should be able to choose AT and equipment that serves their specific needs and choices:

*“We don’t need more organisations telling us ‘That’s not for you’. There’s a lot of decisions made, far away from the people who they’re impacting on, who don’t get access to say, ‘Stop, hang on a sec, that would be of benefit to me’.”<sup>6</sup>*

The significance of access to AT should be centrally reflected in the outcome of the domain:

**Recommendation**

*Include access to AT and equipment within the outcome of the domain, to read: ‘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, and this includes universal access to assistive technology and equipment.’*

Within the draft outcomes frameworks, the sub-outcome related to non-discrimination on the basis of physical location in relation to access to support is an important recognition of the additional barriers accessing services for those living in rural and remote areas. This should also be reflected in the example indicators, either directly associated with ‘Access to services and supports’ or ‘Access to community-based services’. The National Disability Insurance Agency (NDIA) already captures data related to market concentration of NDIS service providers,<sup>7</sup> however this data should also be collated for non-NDIS disability support service providers, to account for non-NDIS participants – the majority of people with disability in Australia.

**Recommendation**

*Include the example indicator: ‘Market concentration of NDIS and non-NDIS disability support service providers’.*

Another dimension of services that is important to consider is stability of services and long-term access. For example, many SCIA members have discussed the specific difficulties involved in establishing meaningful relationships with their support workers, due to the current transient nature of the industry and high staff turnover. These relationships are not simply professional, for many people with disabilities, developing friendships and trust with support workers is a crucial step in feeling welcomed and included in society more generally. As such, the long-term stability of service providers should be taken into consideration either within the example indicator, ‘Client satisfaction’, or within the sub-outcomes.

**Recommendation**

*Either specifically reference client satisfaction with long-term, stable access to the same service provider OR re-phrase the sub-outcome to read: ‘The services and support persons I access are well-coordinated and allow me to develop long-term relationships of trust’.*

<sup>5</sup> Articles 4(f) and (g) of the *Convention on the Rights of Persons with Disabilities*.

<sup>6</sup> Quote from an interview conducted with an SCIA member on 11 November 2020.

<sup>7</sup> See for example, National Disability Insurance Agency (NDIA), *NDIS Quarterly Report to disability ministers*, 30 June 2020, p. 72.

## Implementation and reporting

Regular annual reporting is a vital element in the measurement of progress in the NDS and NDIS outcomes frameworks. This recommendation is made in light of SCIA's past recommendations and former public consultations with stakeholders in the disability sector.<sup>8</sup> Actions that affect, and data that measures, progress towards achieving the outcomes set by the NDS and NDIS, can reveal dramatic impacts on the daily lives of people with disability and their family and informal carers. In turn, this provides an opportunity to quickly address any issues that have arisen over the course of the year and monitor the progress of ongoing programs impacting people with disability and their families and carers. Reports should include identifying annual changes to funding and policy amendments to services and programs. Additionally, reports should provide all available statistics, collated from different stakeholders, relating to:

- Demographics,
- Access to disability and non-disability specific services,
- Participation in economic and social activities,
- Political agency,
- Education, and
- Accessibility and representation in the media.

Additionally, the NDIA should strive to align the current data available in their quarterly reports and their 'Data and insights' page,<sup>9</sup> with the proposed person-centred shared sub-outcomes.

Implementation and monitoring of the outcomes frameworks should be streamlined through a single, independent body that collates information from the numerous stakeholders delivering programs and policies to progress the outcomes of the NDS and NDIS. This will ensure transparency, independence and public accountability. All stakeholders across the disability sector, government and government agencies (including the NDIA) should commit to an ongoing process of information sharing of quantitative data and engagement and consultation with people with disability and their families and carers. This collaboration will ensure that progress towards NDS and NDIS outcomes are measured *holistically*. The independent body that could best facilitate this process might be the AHRC, particularly as the Commission may draw upon its own disability expertise to align data and feedback within the context of the NDS, NDIS and UNCRPD.

## Other issues to consider

It is an important aspect within the proposed approach to monitoring the NDS and NDIS that families and carers are specifically referred to within shared population-level outcomes. Though to give this group further agency and recognition within the outcomes frameworks, it is suggested that shared person-centred sub-outcomes that directly relate to outcomes for families and carers are included. The significance of understanding the experiences of families and carers has already been mentioned in the Economic security section of this submission.

Therefore, SCIA recommends the following:

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<sup>8</sup> See Spinal Cord Injuries Australia, Submission to Department of Social Services, *A new National Disability Strategy – Stage 2 consultations* (30 October 2020) pp. 9-10; Department of Social Services, *Right to Opportunity: Consultation report to help shape the next national disability strategy – Summary Report*, December 2019, p. 6; Social Policy Research Centre, 'Review of implementation of the National Disability Strategy 2010-2020 Final Report', August 2018, p. 37 and Department of Social Services.

<sup>9</sup> National Disability Insurance Agency, 'Data and insights', *NDIS*, 30 September, <https://data.ndis.gov.au/>.

**Recommendation**

*A shared person-centred sub-outcome directly relating to families and carers should be added to the following domains: Economic security, Personal and community support.*

The position paper released by DSS on the development of a new NDS specifically identified a focus on community attitudes and the development of an Engagement Plan as improvements that should be integrated in the new NDS.<sup>10</sup> However, to ensure these inclusions are successful they should be included within the outcomes frameworks as measurement indicators for each domain. Further, they should be expanded to include assessment of the NDIS.

**Recommendations**

*Include a sub-outcome across all domains that relates to the community's attitudes toward people with disability and their understanding of their role in promoting inclusivity within the community and ensure that a shared indicator can be implemented to assess community's attitudes.*

*Include a specific sub-outcome that applies to all domains measuring engagement of people with disability and their families and carers in the monitoring of the outcomes frameworks.*

**Concluding comments**

Successful development and implementation of the outcomes frameworks will ensure that there can be a coordinated effort by all stakeholders to achieve the goals set out by the NDS and NDIS. This involves cooperation between all stakeholders to share information and avoid duplication. However, SCIA would re-iterate that success should be measured through both quantitative data and through direct consultation with people with disability and their families and carers. These consultations should be *ongoing, genuine and thorough* if the frameworks are to be truly effective: "The strength of the NDS is the disability community's sense of ownership of it, driven in part by its extensive consultation processes".<sup>11</sup> The progress of the NDIS should be viewed similarly. SCIA hopes to contribute to future consultations on the outcomes achieved through the NDS and NDIS.

If the Department would like further information or has any queries about the content of this submission, please do not hesitate to contact SCIA.

Kind regards,

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<sup>10</sup> DSS, 'National Disability Strategy: Position Paper', July 2020, pp. 7 and 10.

<sup>11</sup> Australian Civil Society CRPD Shadow Report Working Group, *Disability Rights Now 2019: Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities, UN CRPD Review 2019*, July 2019, p. 5.