



Submission: outcomes frameworks

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

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Contents

ABBREVIATIONS	3
RECOMMENDATIONS	4
1. INTRODUCTION	6
2. ABOUT THIS SUBMISSION	7
3. IMPROVING OUTCOMES	7
3.1. Evidence- and data-driven policy	7
3.2. People with disability are the experts	8
3.3. Human rights approach	9
4. THREE FEEDBACK QUESTIONS	9
4.1. Question one: what we think about the different elements in draft structure for the outcomes frameworks	9
4.1.1. Naming elements of the outcomes frameworks	9
4.1.2. Establishing the outcomes that cover the elements of a flourishing life	9
4.1.3. Examples of improvements and extensions to the proposed national disability strategy outcomes framework	11
4.1.3.1. Opportunity compared with concrete results	11
4.1.3.2. Other conceptual issues for domains	11
4.2. Question two: how to best implement the Outcomes Frameworks to enable governments and stakeholders track the effectiveness of the Strategy and the NDIS	13
4.3. Question three: how to best implement the Outcomes Frameworks to enable governments and stakeholders track the effectiveness of the Strategy and the NDIS	14
4.3.1. ENABLERS What do you think about including community attitudes and universal design as guiding approaches in the new plan?	14
5. BIBLIOGRAPHY	15

Abbreviations

OPA	Office of the Public Advocate (Vic)
NDIS	National Disability Insurance Scheme

Recommendations

Recommendation 1

Disability policy should continue to be strongly informed by the voice and experience of people with disability; evident through their representative organisations, advocacy and self-advocacy organisations, and safeguarding bodies and mechanisms.

Important and necessary reforms that enjoy the widespread support of people with disability, such as those that may emerge from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, should not be delayed or deferred, pending evidence developed from the outcomes frameworks.

Recommendation 2

The outcomes frameworks should adopt a relational definition of disability with the following three elements:

- self-identification of a disability identity or recognition of this by others in close relationship with the person
- the person describing their functional supports needs arising from impairments; with support from those in close relationship with the person, if needed
- acceptance and documentation of the person's support needs in collaboration with others who support the person, if this is necessary.

Medical evidence would not be mandatory, where there was no dispute that the person experienced functional barriers due to impairment. This process acknowledges that individuals with disability have support needs and are the author of their life.

Recommendation 3

The proposed elements of the outcomes frameworks should be renamed so that each domain is comprised of outcomes grouped under a key outcome.

Recommendation 4

The national disability strategy outcomes framework should be examined and further developed so that it includes key outcomes, outcomes, indicators and measures that are fully consistent with a human-rights-based approach for supporting people with disability to lead a flourishing life.

Recommendation 5

The (key) outcomes for the inclusive communities and learning domains should be revised so they are focussed on concrete outcomes, rather than opportunities.

Recommendation 6

The rights protection domain should include an outcome which relates to recognition and pride.

Recommendation 7

The rights protection domain should include an outcome which relates to personal control and autonomy. This outcome will specify that people with disability have control over their environment and receive the support they need to make their own decisions.

Recommendation 8

The rights protection domain should include an outcome which relates to participation in political processes, strengthening and broadening the current reference to 'democratic processes'.

Recommendation 9

The health and wellbeing domain should include a new outcome which relates to the opportunity for sexual satisfaction and reproductive control.

Recommendation 10

The outcomes frameworks should clearly set out enhanced and transparent administrative and accountability arrangements.

Recommendation 11

Financial sustainability should remain at the level of an 'enabler' in the NDIS outcomes framework.

1. Introduction

The Office of the Public Advocate (OPA) is a Victorian statutory office, independent of government and government services that works to safeguard the rights and interests of people with disability.

The Public Advocate is appointed by the Governor in Council and is answerable to the Victorian Parliament. OPA's primary functions include advocacy, investigation, and guardianship services for people with cognitive impairment and mental illness. The Office provides advice, information, and education about laws affecting people with disability and coordinates four volunteer programs, as detailed below.

In 2019-20, OPA was involved in 1792 guardianship matters (950 of which were new), 430 investigations, and 284 individual advocacy matters. The majority (72 per cent) of eligible guardianship clients were NDIS participants, compared with 58 per cent in the previous year. These figures include the 22 individuals who received guardianship and/or advocacy in the transition to community living following the closure of Colanda Residential Services in Colac.

OPA signs NDIS service deeds consenting to services where guardians have the relevant authority. In 2019-20, OPA completed 1477 NDIS service agreements, a 136 per cent increase from the previous year.

OPA is supported by more than 700 volunteers across four volunteer programs, including the Community Visitors Program, Community Guardian Program, Independent Third Person Program and Corrections Independent Support Officer Program.

Community Visitors are empowered by law to make announced or unannounced visits to Victorian accommodation facilities for people with disability or mental illness. They monitor and report on the adequacy of services provided in the interests of residents and patients. They ensure that the human rights of residents or patients are being upheld and that residents are not subject to abuse, neglect or exploitation. In their annual report, Community Visitors report to the Victorian Parliament on the quality and safety of the services they visit.

There are more than 400 Community Visitors who visit across three streams: disability services, supported residential services, and mental health services. In 2019-20, Community Visitors made 1466 statutory visits across all three streams.¹ This was a significant reduction from previous years due to the impact of COVID-19 on visitation

¹ Office of the Public Advocate (Vic). *Community Visitors Annual report 2018-19*.

2. About this submission

The purpose of this submission is to respond to the Public consultations for the NDS and NDIS Outcomes Frameworks Introductory paper.² In line with the requests made within the Introductory paper, this submission will discuss:

- what we think about the different elements in draft structure for the Outcomes Frameworks
- how to best implement the Outcomes Frameworks to enable governments and stakeholders track the effectiveness of the Strategy and the NDIS
- what else to consider when monitoring and measuring the impact of activities on people with disability.

OPA will draw upon our previous submissions to the new Victorian Disability State Plan 2021-2024 (May 2020)³, Rights and Attitudes Issues Paper (August 2020)⁴ and the National Disability Strategy Position Paper (October 2020).⁵

3. Improving outcomes

3.1. Evidence- and data-driven policy

OPA strongly supports the goal of facilitating government, and the broad community, having an acknowledged means for understanding where 'outcomes are improving for people with disability, and where governments and other stakeholders can do more'.⁶ OPA also supports having an evolving library of indicators and measures, which takes advantage of new insights and improving data and measurement opportunities. This should be done in ways that constantly expand and improve data sets, while ensuring the integrity and consistent tracking of long-term changes and trends.

The analysis of emerging trends and long-term issues should be used to inform disability policy and priorities for future investment under the proposed new Strategy and the NDIS.

Disability policy should also continue to be strongly informed by the voice and experience of people with disability; evident through their representative organisations, advocacy and self-advocacy organisations, and safeguarding bodies and mechanisms. The more immediate experience and voice of people with disability, through its different channels, will often be in advance of emerging data trends and must continue to be given due regard in policy responses.

Similarly, important and necessary reforms that enjoy the widespread support of people with disability, such as those that may emerge from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, should not be deferred, pending further evidence developed from the outcomes frameworks.

² Department of Social Services, 2020, Public consultations for the NDS and NDIS Outcomes Frameworks

³ Office of the Public Advocate (Vic.) *Submission to the State Disability Plan 2021-2024* (OPA, 2020).

⁴ Office of the Public Advocate (Vic.) *Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Rights and Attitudes Issues Paper* (OPA, 2020).

⁵ Office of the Public Advocate (Vic.) *Submission to the National Disability Strategy Position Paper* (OPA, 2020).

⁶ Department of Social Services, 2020. Introductory paper: improving outcomes for people with disability under the National Disability Strategy and the National Disability Insurance Scheme

Recommendation 1

Disability policy should continue to be strongly informed by the voice and experience of people with disability; evident through their representative organisations, advocacy and self-advocacy organisations, and safeguarding bodies and mechanisms.

Important and necessary reforms that enjoy the widespread support of people with disability, such as those that may emerge from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, should not be deferred, pending evidence developed from the outcomes frameworks.

3.2. People with disability are the experts

Work still needs to be done to shift the understanding of disability so that all Australians, move towards seeing that authority lies in the experience of the person with disability, and their representative organisations.

As was found in the (Tune) Review of the NDIS Act⁷, people with disability are still not being recognised as the biggest expert on their disability, contrary to the rhetoric on choice and control.

To help shift attitudes, it is necessary to formally adopt a relational approach to defining disability, for the National Disability Strategy outcomes framework. OPA anticipates that the outcomes framework for the National Disability Insurance Scheme will relate to and participants and other people with disability who have applied for eligibility.

At its simplest, a person with disability is a person who identifies as having a disability. Some people with disability will be consistently identified by others in a close relationship with them as having a disability. The latter should not occur where the person has the capacity to adopt or refuse this identity themselves. This is the approach that most people already take in everyday life. This should be mirrored in policy for the outcomes framework.

Recommendation 2

The outcomes frameworks for the National Disability Strategy should adopt a relational definition of disability with the following three elements:

- **self-identification of a disability identity or recognition of this by others in close relationship with the person**
- **the person describing their functional supports needs, arising from impairments; with support from those in close relationship with the person, if needed**
- **acceptance and documentation of the person's support needs in collaboration with others who support the person, if this is necessary.**

Medical evidence would not be mandatory, where there was no dispute that the person experienced functional barriers due to impairment. This process acknowledges that individuals with disability have support needs and are the author of their life.

⁷ David Tune, 2019 Review of the NDIS Act report, Department of Social Services

3.3. Human rights approach

Consistent with Australia's obligations under the United Nations, OPA urges the purposeful adoption of a human-rights basis for the outcomes frameworks.⁸

A human rights approach affirms the inherent worth of every individual and promotes and protects rights. A human rights approach provides real equal opportunity, effective participation and full inclusion in society. It also involves creating a culture, both broadly in society and within organisations, that fosters a human-rights-approach mindset. Culture is the product of our values and our actions, including the words we use.

A human-rights approach:

- sees impairment as an expected dimension of human experience and diversity
- recognises that the vast majority of challenges experienced by people with disability are a result of disabling systems and environments
- challenges attitudes and environments that harm the dignity of people with disability
- requires people with disability to be resourced and supported to have the capabilities to lead a dignifying and flourishing life.

At the policy level under discussion, a human-rights approach provides a rigorous platform for the outcomes frameworks and the accountability measures for actors with responsibilities that flow from such a framework.

4. Three feedback questions

4.1. Question one: what we think about the different elements in draft structure for the outcomes frameworks

4.1.1. Naming elements of the outcomes frameworks

OPA supports the overall architecture of the framework, which enjoys widespread acceptance as an appropriate model for evaluative and performance monitoring frameworks.

OPA has some concerns surrounding elements and approaches of the proposed framework.

The first concern is with the name of the person-centred outcome. The 'sub-' prefix must be entirely avoided, for its past associations. Instead, this 'person-centred' element should be simply called outcomes, while the overarching outcome sitting above these should be called key outcomes, preserving the hierarchy and clarity.

Recommendation 3

The proposed elements of the outcomes frameworks should be renamed so that each domain is comprised of outcomes grouped under a key outcome.

4.1.2. Establishing the outcomes that cover the elements of a flourishing life

The suite of elements of a human-rights approach should be amplified through their take-up in the improving outcomes framework. This can be done by ensuring the eventual set of

⁸ United Nations, 2006. Convention on the Rights of Persons with Disabilities

indicators and measures covers all the elements of the capability-based approach to flourishing human life developed by Amartya Sen and Martha Nussbaum.⁹

In this framework, a flourishing life has these elements:

- **affiliation:**
 - **being able to live with and toward others:** Recognising and showing concern for others. Engaging in social interaction. Being able to imagine the situation of another.
 - **having the social basis for self-respect and non-humiliation;** Being treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin and species.
- **bodily health:** having good health, including reproductive health; being adequately nourished; having adequate shelter.
- **bodily integrity:** Being able to move freely from place to place; being secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and choice over contraception and reproduction.
- **control over environment:**
 - **material:** Being able to hold property (both land and movable goods). Having property rights on an equal basis with others. Having the right to seek employment on an equal basis with others. Having freedom from unwarranted search and seizure. Having meaningful work where you can exercise practical reason and your human potential. Having meaningful relationships and mutual recognition with other workers.
 - **political:** Being able to participate effectively in political decisions that govern life. Having the right of political participation. Protections of free speech and association.
- **emotions:** Have attachments to things and people outside ourselves. Generally, to love, grieve, experience longing, gratitude, and justified anger. Not having one's emotional development hindered by fear and anxiety. Supporting forms of human association that are crucial to a person's emotional development.
- **life:** living a normal human life span; not dying prematurely or having life reduced to a life not worth living.
- **other species:** Being able to live with concern for and in relation to animals, plants, and the world of nature
- **play:** Being able to laugh, to play, to enjoy recreational activities.
- **practical reason:** Being able to form a conception of the good and to engage in critical reflection about the planning of one's life

⁹ Nussbaum, M.C. (2006) *Frontiers of justice: disability, nationality, species membership*.
Sen, A (2009) *The idea of justice*

- **senses, imagination and thought:** Being able to use the senses; to be able to imagine, think, and reason broadly, informed and cultivated by an adequate education, including literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with wide ranging experiences, including religious, literary, musical, and other works and events. Being able to use one's mind in ways protected by guarantees of freedom of expression, including political and artistic speech, and freedom of religion. Having pleasurable experiences and being able to avoid non-beneficial pain.¹⁰

Many aspects of these capabilities for a flourishing life have already been recognised in the development of the outcomes frameworks. All the elements of a human-rights approach to a flourishing life can be included or translated into the frameworks. This expansion can guide the ways that governments, individuals, communities and organisations respond to people with disability, in ways that are also consistent with the Convention on the Rights of Persons with Disabilities.

Recommendation 4

The national disability strategy outcomes framework should be examined and further developed so that it includes key outcomes, outcomes, indicators and measures that are fully consistent with a human-rights-based approach for supporting people with disability to lead a flourishing life.

4.1.3. Examples of improvements and extensions to the proposed national disability strategy outcomes framework

4.1.3.1. Opportunity compared with concrete results

The proposed domains and their outcomes have some stark differences in their wording. Some are more definite than others. For example, the (key) outcome for the Health and wellbeing domain starts with 'People with disability attain the highest possible health...'. This is in contrast with the 'Inclusive and accessible communities' and 'Learning and skills domains, that both are unnecessarily qualified by use of the term 'opportunity for' or 'opportunities to'. Both of these (key) outcomes should be revised so that they mirror the construction of the outcomes, in focusing on concrete results achieved, rather than more nebulous opportunities.

Recommendation 5

The (key) outcomes for the inclusive communities and learning domains should be revised so they are focussed on concrete outcomes, rather than opportunities.

4.1.3.2. Other conceptual issues for domains

OPA notes that there are conceptual problems with the domains, in that in combination they do not adequately cover all aspects of the conditions for a flourishing life.

For example, the presently defined (key) outcome for the Inclusive and accessible communities is as follows:

People with disability live in accessible and well-designed communities with opportunity for full inclusion in social, economic, sporting and cultural life.

The present wording unsuccessfully combines accessible social relationships with accessible places and infrastructure. This matters because while some physical infrastructure and some communities ought to be well designed, other communities are

¹⁰ Babin, C. (n.d.) *Disability Rights, Dr. Martha Nussbaum's 10 capabilities*

organic in nature, and have no designer or owner who could impose a design. These organic communities are where community and everyday life really matter. In this domain there are also currently missing elements such as 'respect', although it could perhaps be accommodated under the notion of 'I feel welcome'.

The conceptual problems for this domain relate to its interplay with the 'Rights protection, justice and legislation' domain and the health domain. Presently, the associated 'key' outcome for rights protection domain is 'People with disability feel safe and have their rights promoted, upheld and protected.'

In combination, these domains need to accommodate many of the requirements for leading a flourishing life including:

- affiliation:
 - being able to live with and toward others
 - having the social basis for self-respect and non-humiliation;
- bodily integrity
- control over environment:
 - material
 - political

Presently, these domains together do not adequately cover all these requirements.

These domains could be strengthened by the more explicit description or addition of elements relating to affiliation, bodily integrity and control over environment.

The rights protection domain should be further strengthened by including outcomes that spring from the capabilities framework described above.

OPA supports having an outcome directly related to recognition and pride, as this strongly relates to the need for affiliation described above, and for monitoring the 'social basis for self-respect and non-humiliation'.

Recommendation 6

The rights protection domain should include an outcome which relates to recognition and pride.

Recommendation 7

The rights protection domain should include an outcome which relates to personal control and autonomy. This outcome will specify that people with disability have control over their environment and receive the support they need to make their own decisions.

In the requirements for a flourishing life described above, control over environment includes participation in politics:

- political: Being able to participate effectively in political decisions that govern life. Having the right of political participation. Protections of free speech and association.

The current rights protection domain includes an outcome of participation in local, state and national democratic processes. This should be strengthened to emphasise these are political decisions and processes, including the right to vote. This is a broader concept than the more limited 'democratic processes', which is currently included.

Recommendation 8

The rights protection domain should an outcome which relates to participation in political processes, strengthening and broadening the current reference to ‘democratic processes’.

Bodily integrity, as described in the capabilities framework above, is being supported to have the capability for:

Being able to move freely from place to place; being secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and choice over contraception and reproduction.¹¹

The current outcomes framework has outcomes related to being able to move freely and community safety. Having an outcome related to the opportunity to have sexual satisfaction is consistent with a human-rights framework founded on supporting people with disability to lead a flourishing life.

Recommendation 9

The health and wellbeing domain should include a new outcome which relates to the opportunity for sexual satisfaction and reproductive control.

4.2. Question two: how to best implement the Outcomes Frameworks to enable governments and stakeholders track the effectiveness of the Strategy and the NDIS

OPA remains concerned that people with complex and challenging support needs are not seeing the benefits of recent reforms and initiatives (in particular, the NDIS) to the same extent as other people with disability.¹² The outcomes frameworks must continue to emphasise that inclusion and a human-rights approach is for all people with disability, without exception. This may mean that particular indicators and measures need to be sensitive and tailored to the experience of people with cognitive and severe disability.

The frameworks also need to be implemented with maximum effect from low-cost and easily implemented indicators and measures. This means using robust and emerging best-practice approaches that have already been developed within the states and territories. The national frameworks should promote national consistency, but not at the expense of losing existing investments in outcomes frameworks.

During the further establishment and implementation of the outcomes frameworks, the voice and experience of people with disability must continue to influence the system of measuring, monitoring and improving outcomes for people with disability. The actual experience of people who are realising the outcomes must continue to be asked about what these outcomes mean for them in their everyday life.

This means there must be enhanced administrative, accountability and governance arrangements, to ensure that the outcomes frameworks actually lead to flourishing lives for people with disability.

¹¹ Babin, C. (n.d.) *Disability Rights, Dr. Martha Nussbaum's 10 capabilities*

¹² Office of the Public Advocate, (2018). *The illusion of 'choice and control'*

Recommendation 10

The outcomes frameworks should clearly set out enhanced and transparent administrative, accountability and governance arrangements.

4.3. Question three: how to best implement the Outcomes Frameworks to enable governments and stakeholders track the effectiveness of the Strategy and the NDIS

4.3.1. What do you think about including community attitudes and universal design as guiding approaches in the new plan?

The status of an 'enabler' is not clear. Enablers such as 'universal design' need to be universal government policy for all programs and operations.

The provisions of the General Obligations (Article 4) of the United Nations Convention on the Rights of Persons with Disabilities require government bodies to take appropriate measures for the implementation of the rights recognised in the Convention. This includes action to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against people with disability. These obligations require that government bodies consider the protection and promotion of the human rights of people with disability in all policies and programs.

Community attitudes are held by community members and embedded in laws, regulations, customs and practices. The lack of inclusion due to the non-provision of universal design constitutes discrimination against people with disability.

Both providing universal design and working towards changing discriminatory community attitudes are the responsibility of government in all activities, policies and programs.

The Inclusion of 'financial sustainability' as an enabler may be justified, if enablers are not to be confused with 'drivers'. Financial sustainability is a means to an end, not an end-in-itself. For this reason, financial sustainability should not be elevated to the status of an outcome.

Recommendation 11

Financial sustainability should remain at the level of an 'enabler' in the NDIS outcomes framework.

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