

A new National Disability Strategy - Stage 2 consultations

Submission process -
Position paper for development of the next
national disability strategy

29 July 2020

Introduction

This submission process will inform the next national disability strategy. There are 9 questions. The questions ask for your feedback on some ideas in a position paper, which has been jointly developed by all Australian governments. The position paper builds on the stage 1 consultations and other previous reviews. This process is part of stage 2 of consultations.

You can also provide a written submission.

Background – Stage 1

During stage 1 (March – July 2019), more than 2,600 people did an online survey. They were people with disability their families and carers, and people in the disability and community sectors. More than 1,000 people also attended community workshops and discussions.

In December 2019, the report arising from the stage 1 consultations, Right to Opportunity: Consultation report to help shape the next national disability strategy, was released on the Department of Social Services website.

In stage 1, we asked about:

- **the barriers people with disability face**
- **what has improved, and what has not**
- **what is important for the next national disability strategy.**

About the submission

Now, we are asking for your specific feedback on governments' proposals for the next Strategy, as set out in the position paper. The proposals include:

- **the vision, outcome areas and guiding principles for the new Strategy**
- **a stronger focus on improving community attitudes**
- **clearly describing roles and responsibilities of governments and the community**
- **regular public reporting that shows whether the key outcomes for people with disability are improving**
- **developing targeted action plans to drive better implementation**
- **how people with disability can be engaged in the delivery and monitoring of the next Strategy.**

The Department of Social Services will collect and analyse your answers and the results will inform development of the next national disability strategy for beyond 2020. Standard words on privacy. Individual responses are anonymous.



Governments acknowledge the challenges people with disability are facing during the COVID-19 pandemic. We appreciate the time taken to provide feedback on the positions outlined in the position paper.

Support to help you complete the survey

You can get help to do this survey. You can:

- **Ask a friend, family member or support person to help you**
- **Call 1800 334 505 and someone from the Department of Social Services will help**
- **Call 1800 334 505 using the National Relay Service 13 36 77 if required and someone from the Department of Social Services will help**
- **Email disabilityreform@dss.gov.au with any questions or concerns.**

About you

Are you responding as an individual or as a representative of an organisation?

**If you are responding as an organisation your responses may be published and attributed to your organisation in public reporting.*

I'm responding as an individual	<input type="checkbox"/>
I'm representing an organisation (please provide the name of your organisation)	<input checked="" type="checkbox"/>

Which of the following statements best describes you? Please select all that apply.

I'm a person with disability	<input type="checkbox"/>
I'm a parent / guardian or other family member of a person with disability	<input type="checkbox"/>
I'm a carer of a person with disability	<input type="checkbox"/>
I'm a support worker / work directly with people with disability	<input type="checkbox"/>
I'm a disability advocate and/or work for a disability peak association or service provider	<input type="checkbox"/>
I employ people with disability	<input type="checkbox"/>
I'm a business owner	<input type="checkbox"/>
I'm a health professional	<input type="checkbox"/>
I'm a researcher or academic	<input type="checkbox"/>
I'm employed by federal, state or territory, or local government	<input type="checkbox"/>
Other (please specify): Non-government organisation staff member, Advance Care Planning Australia	<input checked="" type="checkbox"/>

Which state or territory do you live in?

Australian Capital Territory	<input type="radio"/>
New South Wales	<input type="radio"/>
Northern Territory	<input type="radio"/>
Queensland	<input type="radio"/>
South Australia	<input type="radio"/>
Tasmania	<input type="radio"/>
Victoria	<input checked="" type="checkbox"/>
Western Australia	<input type="radio"/>
I do not live in Australia	<input type="radio"/>
Prefer not to say	<input type="radio"/>

Which type of geographic location do you live in?

A capital city	<input checked="" type="checkbox"/>
A regional city or town	<input type="radio"/>
A remote town or area	<input type="radio"/>
Prefer not to say	<input type="radio"/>

Do you identify as Aboriginal and/or Torres Strait Islander?

Yes	<input type="radio"/>
No	<input checked="" type="checkbox"/>
Prefer not to say	<input type="radio"/>

Are you from a culturally or linguistically diverse background?

Yes (please provide more information)	<input type="radio"/>
No	<input checked="" type="checkbox"/>
Prefer not to say	<input type="radio"/>

Do you identify as a member of the LGBTQI+ community?

Yes	<input type="radio"/>
No	<input type="radio"/>
Prefer not to say	<input checked="" type="checkbox"/>

Guided questions on proposals in the Position Paper

Vision and Outcome Areas

Reviews and consultations have told us that the six outcome areas in the current strategy are still the right ones. Therefore, the Government proposes keeping these outcome areas in the next Strategy.

It is important to keep an aspirational vision in the new Strategy to guide disability policy in Australia. Governments are suggesting to keep the current vision in the new Strategy, except to change the word 'citizen' to 'members of the community'.

The proposed vision is:

An inclusive Australian society that enables people with disability to fulfil their potential as equal members of the community.

There are six outcome areas in the current strategy, which are proposed to continue in the new Strategy. Outcome areas guide the areas in which the strategy seeks to improve outcomes for people with disability. They are:

- **Economic security**
People with disability have economic security, enabling them to plan for the future and exercise choice and control over their lives. Economic security can include things like having an income and having a job.
- **Inclusive and accessible communities**
People with disability live in accessible and well-designed communities with opportunities for full inclusion in social, economic, sporting and cultural life.
- **Rights protection, justice and legislation**
People with disability feel safe and have their rights promoted, upheld and protected.
- **Personal and community support**
People with disability, their families and carers have access to a range of well-coordinated and effective disability services and supports that are appropriate for their needs.

- **Learning and support**

People with disability have opportunities to participate in high-quality education system that is responsive to their needs. People with disability have opportunities to continue learning throughout their lives in both formal and informal settings.

- **Health and wellbeing**

People with disability attain the highest possible health and wellbeing outcomes throughout their lives.

Question 1**Do you have any comments on the vision and outcome areas being proposed for the new National Disability Strategy?**

For example, you might like to provide advice on any specific issues within the outcome areas that you think need a particular focus in the next Strategy.

Please provide your response in space provided below (250 word limit).

Advance Care Planning Australia ([ACPA](#)) is the national authority on advance care planning and is funded by the Australian Government. Advance care planning and ability to document Advance Care Directive(s) (preferences for health care and/or appointment of a substitute decision-maker) is relevant for all Australian's with decision-making capacity. All jurisdictions have advance care directive related legislation, common law or policy. The National [Framework](#) for Advance Care Planning Documents (currently under review) provides priorities regarding advance care planning, promotes best practices and ethical based decision making. National quality standards for health service organisations and aged care service providers, are inclusive of advance care planning priorities.

An Advance Care Directive allows a competent adult to consent to, refuse, withdraw and/or appointment a substitute decision-maker for future health care decisions, for a time when they no longer have decision-making capacity. Advance Care Directives are legally binding and health practitioners have responsibilities to access and enact directions.

People with disability that have capacity, have the right to access advance care planning and Advance Care Directives to promote autonomy, choice and rights-based future health care decisions. People with disability that have diminished or no capacity, may have an Advance Care Plan documented on their behalf by their substitute decision-maker or health professional to inform future care but they are not legally binding.

Outcome areas *Rights protection, justice and legislation* and *Health and wellbeing* should be inclusive of advance care planning and advance care directive priorities and principles. Priorities may include the following statements:

- People with disability should be encouraged to participate in advance care planning, and when possible document preferences in an Advance Care Directive.
- People with disability should be encouraged and supported to make their own health care decisions when possible.
- Service providers should understand and have capability in advance care planning, Advance Care Directives and enacting a person's values and preferences during loss of capacity.
- Service providers and health practitioners should understand and have capability in advance care planning and advance care directive related legislation, including who can write and sign documentation on behalf of a person who is unable to physically sign documentation.
- People with disability have the right to informed consent. If the person no longer has capacity, consent should be obtained from the substitute decision-maker and taking into account any

Advance Care Directive (or similar).

- The substitute decision-maker(s), for a person with disability, should be involved in medical treatment decisions when the person is unable to make their own decisions. Their involvement in the person's care should align with jurisdictional advance care directive related legislation, being mindful of privacy considerations.
- People with disability at their end of life, have the right to refuse medical treatment or to request the withdrawal of treatment already started. (Note: reference for statement is <https://www.medicalboard.gov.au/Codes-Guidelines-Policies.aspx>; Good medical practice: a code of conduct for doctors in Australia 2020)

Note: The outcome areas for the next Strategy would continue to guide actions. It is also proposed they be the foundation for a new Outcomes Framework. The proposed Outcomes Framework would provide a clear and consistent approach across all levels of government to measure how effective mainstream and disability-specific services are at improving outcomes for people with disability. You will be able to have a say on a draft Outcomes Framework through a separate public submission process.

Guiding Principles

Guiding principles will help to guide governments when they design and deliver policies and programs. They will also guide the actions of the non-government and private sectors to ensure the inclusion of all people with disability. You can read more about the principles in the position paper on page 7.

In addition to the principles set out in [Article 3 of the UN CRPD](#), an agreed set of guiding principles could include:

- **Involve and engage:**
has the policy or program designer engaged with and listened to people with disability?
- **Design universally:**
have the principles of universal design been applied where possible?
- **Engage the broader community:**
how has the broader community been informed of, involved in and made responsible for removing barriers and supporting the inclusion of people with disability?
- **Address barriers faced by priority populations:**
how have the priority populations (noted by the National Disability Strategy) been identified?
What action has been taken to specifically address the barriers they may experience?
- **Support carers and supporters:**
how have the needs of the family, carers and circles of information and formal support for the person with disability been considered?

The new Strategy must include ways to make sure different types of organisations and individuals adhere to the guiding principles, including ensuring they understand and can effectively use the principles. This could be done through:

- training and information sharing by people with disability who have lived experience
- providing clear information about what each principle means
- sharing case studies of how organisations or programs are applying the principles in action
- a checklist for organisations of the steps they could take to put the principles into action.

Question 2:

What do you think about the guiding principles proposed here?



In responding to this question you might like to think about:

- **Are there other principles that would help ensure policies and programs are right for people with disability, their family and carers?**
- **What information or guidance could help organisations to use and adhere to these principles?**

Please provide your response in space provided below (250 word limit).

At present, the guiding principles do not reference the need to consider the legal rights of people living with disability as part of the process of developing policy and programs. It is likely that the explicit inclusion of a guideline directing policy and program makers to consider and account for legislation related to the rights of the disabled community may help create a more robust, equitable approach. This may include providing information summarising or listing the relevant legislation that should be considered, and recognising that legislation may differ across jurisdictions.

A stronger focus on community attitudes

In the first stage of consultations, people with disability said one of the biggest barriers they face in fully participating in society is community attitudes. This includes in professional and community life.

If community attitudes improved, they said this would help to improve their employment opportunities, financial security, access and involvement in the community.

All levels of government and all parts of the community share the responsibility to shape positive and disability-inclusive attitudes. We all play a part in helping people with disability to fully participate as equal members of the community.

A key focus of the new Strategy will aim to support and foster ongoing attitudinal change across Australian communities so that we harness the rich contribution people with disability make to our society.

Question 3

What is your view on the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas?

Please provide your response in space provided below (250 word limit).

This strategy should also aim to target misinformed attitudes in the health sector, as there are significant documented issues related to people living with disability not having their choices respected. See:

1. Cithambaram K, Duffy M, Courtney E. Disclosure and plan of care at end of life: Perspectives of people with intellectual disabilities and families in Ireland. *British Journal of Learning Disabilities*. 2020 Jul 30.
2. Voss H, Vogel A, Wagemans AM, Francke AL, Metsemakers JF, Courtens AM, de Veer AJ. Advance care planning in palliative care for people with intellectual disabilities: a systematic review. *Journal of Pain and Symptom Management*. 2017 Dec 1;54(6):938-60.
3. Cardona M, Lewis E, Shanmugam S, Nicholson M, Williamson M, Hanly L, Hillman K. Dissonance on perceptions of end-of-life needs between health-care providers and members of the public: Quantitative cross-sectional surveys. *Australasian journal on ageing*. 2019 Sep;38(3):e75-84.
4. Ninnoni JP. A qualitative study of the communication and information needs of people with learning disabilities and epilepsy with physicians, nurses and carers. *BMC neurology*. 2019 Dec 1;19(1):12.
5. Hawkins B, Costello K, Veinot T, Gibson A, Greyson D. Health information behavior research with marginalized populations. *Proceedings of the Association for Information Science and Technology*. 2017;54(1):562-5.



The following questions relate to the goal of strengthening accountability in the new Strategy.

Clearly describing roles and responsibilities

All Australians have a role to play in achieving an inclusive Australian community.

The new Strategy will **strengthen accountability**. It includes a proposal to **clearly describe the roles and responsibilities** for disability policy and service delivery in Australia.

This includes the responsibilities of different levels of government and non-government organisations, such as community services and the private sector.

The Strategy proposes to bring together a range of publicly available information into one spot. The information would clarify governments' roles and responsibilities for:

- **supporting people with disability**
- **supporting NDIS participants**
- **supporting the people with disability in Australia who are not eligible for the NDIS.**

Question 4

How do you think that clearly outlining what each government is responsible for could make it easier for people with disability to access the supports and services they need?

Please provide your response in space provided below (250 word limit).

Clearly outlining responsibilities will help facilitate change across these areas. However it may also be beneficial to explicitly refer to the responsibilities for those working in the health sector, as well as those working in community settings and the private sector.

It would also be beneficial to explicitly reference the responsibilities of healthcare providers and healthcare organisations, including the recognition of self-determination related to health care for people living with disability. Including explicit information for organisations, health practitioners, and non-registered health practitioners (eg. disability support worker) to actively engage in supportive decision-making, advance care planning and/or enacting an Advance Care Directive. The National Framework for Advance Care Planning Documents (currently under review) places obligations on both registered and non-registered health practitioners to implement a person's values and preferences to inform health care decisions.

These responsibilities should specifically refer to the rights of people living with disability to plan for their future healthcare needs and produce Advance Care Directives or other advance care planning documents.

Question 5

How do you think the Strategy should represent the role that the non-government sector plays in improving outcomes for people with disability?

(Examples of the non-government sector include big, medium and small businesses, community organisations, employees of these businesses, private research, investment organisations and individuals).

For example, you might like to suggest a way the Strategy could better guide non-government organisations to improve inclusion and equity for people with disability. This could include their role in communities, the workplace, or as part of delivering services.

Please provide your response in space provided below (250 word limit).

Reporting

Reporting is an important part of the Strategy's goal of **strengthening accountability** (refer position paper page 9).

Current strategy reporting is done through periodic implementation plans and progress reports. The Australian Government compiles these with input from state, territory and local governments. However, there are concerns this approach does not:

- **give people enough visibility of whether the Strategy is making a difference**
- **guide actions or hold governments accountable.**

Reviews and consultations have suggested more frequent and different types of reporting. For example, the Productivity Commission recommended a National Disability Report be prepared every two years. In consultations, many stakeholders suggested annual reporting.

The position paper suggests reporting options for the next Strategy may include:

- **the responsible Ministerial Council releasing an annual, public statement outlining government policy commitments to lift outcomes for people with disability**
- **a progress report to be published every two years that uses the new Strategy's Outcomes Framework to:**
 - **assess whether outcomes for people with disability are improving**
 - **identify government policy and program contributions towards achieving these outcomes for people with disability.**

Page 9 of the position paper contains more information about the proposed Outcomes Framework.

These reporting options could provide clearer information to the public on whether government policies and programs are making a difference for people with disability, rather than listing government activities without assessing whether these activities are effective.

Question 6

What kind of information on the Strategy's progress should governments make available to the public and how often should this information be made available?

In providing a response to this question, you might like to think about:

- **What type of reporting would help you know whether the lives of people with disability in Australia are improving?**
- **How often should reporting be done?**

Please provide your response in space provided below (250 word limit).

As per the response from the UN on the previous NDS strategy, it would be beneficial for progress reports to explicitly report on outcomes and measurements related to access and equity for Aboriginal and Torres Strait Islanders living with disabilities, children living with disabilities, and for women and girls living with disability. In particular, target benchmarks to improve access to services and support for these groups, and especially for women and girls of Aboriginal and Torres Strait Islander descent living with disability should be included in yearly and/or two-yearly reports.

Reports could also include a measure of whether people living with disability are provided with opportunities to engage in advance care planning, the prevalence of Advance Care Directive documentation in the person's health record, and/or whether directions included in Advance Care Directives for people living with disability are adhered to by health practitioners. In addition, consumer experience data could include questions regarding attitudes towards, perspectives of and/or experience with advance care planning.



The following questions relate to the Strategy’s goal of putting policy into action to achieve outcomes for people with disability through policy development and program design.

Targeted Action Plans to drive implementation

The current strategy had periodic implementation plans. The proposal for the new Strategy is for an **Outcomes Framework** and subsequent evaluations to provide a more coordinated and cohesive approach to measuring the effectiveness of programs people with disability use. All governments could also work towards aligning their disability inclusion plans. Aligning timeframes would make implementation, reporting and review nationally consistent.

Targeted Action Plans are a specific proposal to improve implementation under the next Strategy (refer position paper page 11).

Governments would work with each other and the non-government sector on a particular topic, for a certain period of time, to make the improvements needed. The Targeted Action Plan would involve committing to delivering actions within a set timeframe. This would contribute to improving outcomes for people with disability.

What these Targeted Action Plans cover would be settled as part of implementation of the Strategy. They would allow the Strategy to respond and adapt to the changing needs of people with disability.

Question 7

What do you think of the proposal to have Targeted Action Plans that focus on making improvements in specific areas within a defined period of time (for example within one, two or three years)?

In responding to this question, you might like to think about specific topics, areas or strategies you think Targeted Action Plans should focus on.

Please provide your response in space provided below (250 word limit).

A Targeted Action Plan regarding advance care planning and Advance Care Directives to promote health care rights and access to preference aligned care would be beneficial.

Advance care planning has many known benefits for the general population, substitute decision-makers, health practitioners and service providers. There is currently a limited understanding of advance care planning uptake for people with disability and their service providers. Given the evidence that people living with disability may have information about their health and treatment options withheld by health practitioners and/or their carers, it is vital that some focus is placed on ensuring the values, preferences and choices of people living with disability are being respected.

Engagement with people with disability

The first stage of consultation confirmed that people with disability expect to be more involved in disability policy development and program design (refer position paper page 11). Participants of stage 1 consultations said this would make policies and programs more effective.

It is proposed the next Strategy include an **Engagement Plan**. The Plan would state how governments will ensure people with disability can lead and shape disability policies, programs and services.

Question 8

How could the proposed Engagement Plan ensure people with disability, and the disability community, are involved in delivering and monitoring the next Strategy?

When answering this question, you might like to provide advice about specific strategies or actions that could go into an engagement plan so that people with disability have more say in how the Strategy is monitored and delivered.

Please provide your response in space provided below (250 word limit).

Although many individuals living with disability would be best placed to respond to this question, it is worth highlighting that some efforts targeting those who have acquired disabilities, including disability produced by the ageing process, are included in the Engagement Plan. For many with acquired disability, they will have experience of the community and care systems from more than one perspective, and may be able to help pinpoint specific inequalities that may not be readily apparent to other groups.

Additional information

Stage 2 of the national disability strategy consultation process will inform:

- specific sections in the next Strategy
- how we will implement it.

Question 9

Is there anything else you would like to share about the ideas and proposals in the position paper?

Please provide your response in space provided below (1000 word limit).

The rights of people living with disability to be involved in deciding their future health care is often left out of conversations about improving equity, access and empowerment of the disabled community. However, there is evidence that these individuals will often experience discrimination in healthcare settings because of a presumed lack of ability to understand or engage in these conversations.(1-5) Despite this, all Australians have the right to actively engage in decisions about their health care.(6) These rights are protected by law, and one such right is the right to engage in advance care planning to ensure future health care aligns with a person’s preferences for care. (7)

To facilitate the inclusion of advance care planning in the next strategy, we have provided a brief summary of the advance care planning process and sources of additional information that could be included:

Advance care planning is the process of planning for future health and personal care needs. It provides a way for a person to make their values and preferences for future medical care known. Advance care planning documents are then used to help guide decision-making at a future time if and/or when the person cannot make or communicate their decisions. Advance care planning is an ongoing process that should be undertaken early and revisited regularly. Engaging in advance care planning helps people to determine their healthcare priorities and align their health and care preferences with the actual care they receive.

There is no national advance care directive legislation in Australia. Each jurisdiction determines legislation or policy about Advance Care Directives for documenting preferences of care and/or appointing substitute decision-makers. The law exists to allow people autonomy and choice in their future medical treatment decisions, including consent, withdrawal, refusal, or substitute decision-making.

All Australians have the right to self-determination and can choose to consent or not consent to health treatments. However, there may be times where a person’s capacity to make informed decisions about their care is diminished. When this happens, Advance Care Directives are an important tool for a person to pre-emptively provide important information about their healthcare priorities and preferences. An

Advance Care Directive is a voluntary, person-led document completed and signed by a competent person describing the person's values and preferences for future medical treatment decisions, including their preferred outcomes and care. An Advance Care Directive may include binding instructions regarding consent, refusal, or withdrawal of medical treatment, and may also be used to appoint a substitute decision-maker who can make decisions about health or personal care on the person's behalf.

If a person has diminished or no capacity, they are still able to have someone (preferably the substitute decision-maker) document their preferences in an Advance Care Plan. Although Advance Care Plans do not have the same legal standing as an Advance Care Directive, it can still be used to inform care by providing the substitute decision-maker or treating health professionals with important information about what the person does and/or does not want in terms of the care they receive. Advance Care Directives only come into effect when the person loses decision-making capacity. If the loss of capacity is only temporary (e.g. delirium related to illness or treatment), the Advance Care Directive will only be in effect until the person regains decision-making capacity.

More information about advance care planning, including access to forms, can be found on the Advance Care Planning Australia [website](#) and legal resources hub. Alternatively, a national advance care planning advisory service 1300 208 582 is also available for consumers, the health and disability care workforce, and service providers.

References:

1. Cithambaram K, Duffy M, Courtney E. Disclosure and plan of care at end of life: Perspectives of people with intellectual disabilities and families in Ireland. *British Journal of Learning Disabilities*. 2020 Jul 30.
2. Voss H, Vogel A, Wagemans AM, Francke AL, Metsemakers JF, Courtens AM, de Veer AJ. Advance care planning in palliative care for people with intellectual disabilities: a systematic review. *Journal of Pain and Symptom Management*. 2017 Dec 1;54(6):938-60.
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6. Haining C, Nolte L, Detering KM. 2019. Australian advance care planning laws: Can we improve consistency? Austin Health, Melbourne: Advance Care Planning Australia.
7. Carter RZ, Detering KM, Silvester W, Sutton E. Advance care planning in Australia: what does the law say?. *Australian Health Review*. 2016 Aug 26;40(4):405-14.