

# Consultation report for

Guide to Applying Australia's Disability Strategy 2021–2031

and

Toolkit for engaging with people with disability in evaluation

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We acknowledge the significant effort and time of organisations who supported people to contribute.

We also thank the Disability Advocacy Network Australia (DANA) for facilitating targeted consultations and consolidating their findings to support development of the *Guide to Applying Australia's Disability Strategy 2021–2031* and *Toolkit for engaging with people with disability in evaluation*.



#### **Executive summary**

Australia's Disability Strategy 2021–2031 (the Strategy/ADS) is Australia's policy framework that provides national leadership towards an inclusive Australian society. It aims to ensure people with disability can fulfil their chosen potential as equal members of the community.

ADS recognises that all levels of government are jointly responsible for supporting this vision. It also recognises working closely with the disability community, businesses, the non-government and services sectors is needed to drive positive change.

Under the Strategy, governments committed to develop 3 guides. In this report, we refer to them collectively as 'the Guides'.

#### They include:

- The Good Practice Guidelines for Engaging with People with Disability. Released in 2023, it provides practical tools to support the inclusion of people with disability in community consultation, policy development and government decision-making.
- The Guide to Applying Australia's Disability Strategy 2021–2031 (the Guide). This provides practical guidance for businesses and employers, community organisations and public servants at all levels of government when applying the Strategy's Principles. This guide was released in 2024.
- The Toolkit for Engaging with people with disability in evaluation (the Toolkit). This
  provides practical advice and tools for those conducting evaluation activities and for
  people with disability who are involved in evaluation to understand what to expect
  and how to contribute. The Toolkit was previously known as the Guide to Involving
  People with Disability in Evaluation.

This report was completed in 2023. Publication was delayed until the Guides were ready. An additional section has been drafted as a preface to accommodate consultation and testing on the Toolkit was released in 2025.

The department, with the support of partnering organisations, held meetings, workshops and focus groups. These activities are referred to as consultations. This report sets out the comprehensive consultation findings from that period. Further consultation and final testing occurred in late 2024 to early 2025 and is summarised in the preface. The collective feedback received through consultation shaped the development of the Guide and the Toolkit.

#### 2025 preface

This preface summarises consultation that occurred in 2024 and 2025 to finalise and publish both the Guide and the Toolkit. The remainder of the report explains the feedback gained across 2022 and 2023.

In late 2024 the Guide underwent final review through several established governance groups managed by the Department of Social Services, with members of Australia's Disability Strategy Disability Representative Organisations Forum, Australia's Disability Strategy Advisory Council, State and Territory Officials through the Disability Senior Officials Group, and Commonwealth Agency colleagues.

The Guide was provided to the <u>Disability Reform Ministerial Council</u> in late 2024 for members to note and was published online 3 December 2024. You can get copy of <u>the Strategy Guide on the Disability Gateway website</u>.

In 2025 the Toolkit was further developed to support the commencement of the Independent Evaluation of Australia's Disability Strategy. You can get a copy of <a href="the Toolkit">the Toolkit</a> on the Disability Gateway website.

#### **Summary of 2025 engagement**

Consultation in 2025 for the Toolkit occurred with:

- Queenslanders with Disability Network (QDN), organised for the policy advisory group to review Toolkit in May
- members at the Disability Representative Organisations (DRO) Forum in May
- approximately 30 evaluation professionals at a session by the Australian Centre for Evaluation in late May
- a session with members of the department's Disability and Carers Stream Evaluation Community of Practice in late May
- feedback from colleagues in the Department of Social Services (DSS) supported employment policy area
- feedback from the National Disability and Research Partnership, the National Disability Insurance Agency (NDIA) and Australian Human Rights Commission
- Australia's Disability Strategy Advisory Council provided direction and feedback and endorsed the Toolkit in July
- states and territories reviewed and provided redline feedback.

Through this process we heard from approximately 130 people who provided verbal and written commentary that shaped the first and second iterations of the Toolkit. The engagement and advice provided was generously given and exceptional in quality.

#### Feeback and responses

## Amount of detail and how to use the Toolkit for engaging with people with disability in evaluation

Some requests were for more information to be included and other suggestions were for less content and for the Toolkit be shorter.

We increased the content on trauma-informed approaches, more detail on remuneration and what process to follow, information on ethical considerations and informed consent. When consulting on the Toolkit, people clearly said they wanted practical advice, tools and resources.

To accommodate accessibility and different engagement styles, the Toolkit is available in both screen readable versions and in sections for people who would prefer to engage in smaller chunks.

The Toolkit itself is divided into 3 separate parts that could be read together but do not need to be. Part 1 provides information for people with disability, their families and allies to get engaged in evaluation. Part 2 of the Toolkit is aimed at organisations commissioning evaluation and evaluators, and bridges the gap between evaluation practise and inclusive practise.

Part 3 is the collection of fact sheets and checklists which are the resources, tools, examples and supporting links people have requested through feedback. Once the reader is familiar with the core Toolkit, that is Part 1 and 2, they can continue to access and utilise the tools at Part 3.

The Toolkit will set a precedent for good practice and give guidance to those who are disability confident and aware, but more importantly to those who are not yet confident or aware.

#### Accessibility

Feedback included a need for accessibility checks and an explanation video to support rollout. Expectations of features include Easy Read versions of the Toolkit, printed versions to be available, as well as access online. The feedback included seeking a way for people to listen to the whole Toolkit, as well as to access just the part they needed.

#### Privacy and ethics

While there was information on privacy and ethics in the draft Toolkit, feedback received called for these sections to be bolstered, not only for people with disability but particularly for evaluators, to give plenty of guidance for those working this space, including those commissioning or asking for evaluation to happen.

Evaluation practitioners indicated they appreciated the Toolkit addressing the intersection which is privacy and ethical considerations when working with people with disability in evaluation.

This feedback informed further iterations to the Toolkit.

#### Data sovereignty and governance

We received feedback that the principles of Indigenous Data Sovereignty and Governance should guide all data-related activities involving First Nations peoples, as these principles affirm the rights of First Nations peoples around the collection and use of their data. We included reference to both sets of principles in the Toolkit.

#### Power sharing vs participation

We received feedback to focus more on the active role that people with disability can take in the leading, development, co-design and implementation of evaluation. We appreciated this feedback on language around shared power and leadership and included linkages with disability-led principles and modified the focus accordingly.

#### Language

We received feedback on some points of language and definitions, for example 'reasonable adjustments' versus 'accommodations made' and the need to clarify cultural safety. Within the evaluation community there is accepted 'evaluation' language that professionals use often to describe evaluators, commissioners or funders, which is all ways of describing who is planning, paying or asking for an evaluation of a project to happen.

We also received feedback from multiple places on the need for plain English and nonbureaucratic language.

We appreciated robust discussion on these language points and balanced the use of known language with the need to communicate plainly and simply in the Toolkit.

#### Remuneration

We received a lot of feedback on this topic or often questions from various people asking how to determine how to pay people for their time and what framework to use. After talking to many groups about remuneration and making clear call-outs for people to share what guidance or frameworks they follow, it remains that there is no one set framework to follow. For example, there are governance models and sitting fees, there are incentive payments and vouchers and there is what social and market research companies suggest paying people.

There are various rates and ways to remunerate and recognise peoples' contributions. We considered the overall theme of remuneration in the Toolkit to be a highly important point and concluded the key here is the importance of recognising the contributions of individuals and providing transparent information to enable paying people for their time.

#### Collaboration and co-design

We received mixed feedback around definitions of co-design and collaboration, including how to do it and how it should be referenced in the Toolkit. We note these topics are very important to people and there are many definitions and perspectives out there.

As a theme however, it is apparent the essence of what people were saying when discussing co-design, collaboration or any other definition, is the call to action to put the user at the centre of the design. Better yet, to empowered the user to establish the design, planning and methods of a process, to partner or lead in the design, execution and decision-making. In this case, the 'user' being people with disability, and the 'process' being evaluation activities.

We appreciated the feedback we received on this topic, and considered established frameworks like the International Association for Public Participation (IAP2), the Good Practice Guidelines for Engaging with People with Disability and various other reference points to capture the essence and meaning of these points and develop the final language in the Toolkit.

#### Families, siblings of people with disability and intersectionality

We received feedback for more reference and inclusion of family members and siblings of people with disability. On this guidance we included those references into the Toolkit.

There were also points around intersectionality and considering how this is presented in a way that does not focus on compounding disadvantage, but recognitions of experience and how they work together. We think intersectionality is very important to discuss and essential for evaluators to consider when engaging with people with disability in evaluation and have made updates on these sections.

#### Closing the loop

We received feedback from many sources that there is insufficient feedback post engagement with evaluation processes. Common feedback is around the need to build in a 'closing the loop' step so that those involved know how to ask for more information and understand an outcome they contributed to, and those managing the task build this into the project planning so it's not an afterthought. Closing the loop includes producing written, verbal or video reports in formats that people can access and actively sharing the information in a prompt way.

#### Attribution and resources

We received many resources, links and examples and we thank all contributors. We have linked these other very useful tools and reading materials throughout the Toolkit, most of which are in Part 3. Where we know the original source, we have attributed their work to them.

#### Thank you

Finally, with thanks for the support through the process to our evaluation partners in the department for the partnership and collaboration we gained to finalise the Toolkit. We appreciate your support and evaluation expertise.

Read on for detail on the consultation activities and feedback gained across 2022 to 2023.

#### **Engagement summary: 2022 to 2023**

#### **Engagement approach**

Some of the questions the department asked people with disability during the consultations are considered open-ended. This means they ask for bigger answers beyond 'yes' or 'no'. Many people shared personal stories about living with disability to help governments better understand how to offer supports and services.

Please note that while the report does not mention all stories and examples provided during the consultation, all experiences shared informed the development of the 3 guides.

Engagement on the development of the Guides included the following stages.

## Development of public consultation papers and the consultation approach

The department worked closely with:

- state and territory governments
- Australian Government agencies
- the Strategy's Advisory Council
- the Strategy's DRO Forum
- Rosemary Kayess, Chairperson of the United Nations Committee on the Rights of Persons with Disabilities, Senior Research Fellow at the University of NSW Social Policy Research Centre, Senior Lecturer UNSW Faculty of Law
- Mary Mallett, CEO of the Disability Advocacy Network Australia (2022)
- the Australian Human Rights Commission.

The department produced the consultation papers in the following formats:

- the full-length consultation paper
- a short summary
- Easy Read
- Auslan and Braille with the option for people to share audio and video responses
- 13 languages translations, including Chinese, Spanish, Korean and Arabic.

#### Public submission process

The department asked a series of questions to people online about what they would like to see included in the Guides. This process is referred to as the public consultation.

The department encouraged people to provide feedback, including:

- people with disability, their families, carers and representatives
- policy makers
- academics
- businesses
- community organisations
- people working in the disability sector.

See Appendix 2 for a list of organisations who provided submissions.

The department promoted consultations for the Guides through its website, its social media platforms, other agencies' social media platforms and stakeholder/subscriber emails.

See Appendix 3 for a full list of channels used to promote consultation and engagement.

#### Disability Representative Organisation workshops

The department facilitated a workshop with Australia's Disability Strategy DRO Implementation Working Group on the Guides.

See Appendix 2 for DRO's who took part in the workshops.

#### Academic roundtables

The department facilitated a roundtable with academics on the 3 guides.

See Appendix 2 for a list of institutions represented by individual academics.

### Targeted focus groups coordinated by Disability Advocacy Network Australia

The Department looked to capture the voices of diverse, intersectional, and harder to reach groups of people with disability. Disability Advocacy Network Australia (DANA) in their national coordination function, coordinated with several DROs who ran targeted focus groups.

These DROs held 16 targeted focus groups, engaging with 111 people with disability. From the targeted focus groups, DROs received insights, examples and lived experiences directly from people with disability.

See Appendix 2 for a list of participating DROs and more information.

## Feedback from states and territories and Australian Government agencies

The department sought feedback on each consultation paper from state and territory representatives and Australian Government agency representatives through the Strategy's governance groups.

The department has included feedback from these groups in this paper only where it offers more information or views to those provided in the above engagement activities.

#### **Engagement snapshot**

#### Guide to Applying Australia's Disability Strategy 2021–2031

Written submissions	Number
Individual submissions	11
Submissions by organisations	23
Total written submissions	34

Face-to-face consultation	Participants
Targeted focus groups via DRO	85
Academic Roundtables	9
DRO Group Sessions	8
Total participants	102

#### Toolkit for engaging with people with disability in evaluation

Written submissions	Number
Individual submissions	11
Submissions by organisations	12
Total written submissions	23

Face-to-face consultation	Participants
Targeted focus groups coordinated by DANA	87
Academic Roundtables	8
DRO Group Sessions	9
Total participants	104

#### Summary of 2022 to 2023 feedback

## Guide to Applying Australia's Disability Strategy 2021–2031

Consultation found that people wanted to see the following themes covered in the Guide:

- An emphasis on the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and relevant legislation.
- A focus on equity.
- A focus on safe and accessible complaints processes.
- The inclusion of information about disability competency and responsiveness training for service providers, and general disability awareness.
- Clear examples of how the concept of intersectionality can be applied for better outcomes.
- A focus on accessibility including safe communication.
- · Advice on how to implement Universal Design.
- An emphasis on safety for children and young people.

Summary of feedback provided by people for each of the 8 the UN CRPD principles covered in the Guide to Applying Australia's Disability Strategy 2021–2031

Principle	Feedback to consider in drafting
Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons	<ul> <li>Include supported decision-making</li> <li>Allow people enough time to make decisions</li> <li>Emphasise accessible communication</li> <li>Ensure choice and control is supported</li> </ul>
2. Non-discrimination	<ul> <li>Explain what discrimination is</li> <li>Ensure messaging makes it clear that discrimination is prohibited</li> <li>Include information on education to prevent discrimination</li> </ul>

Principle	Feedback to consider in drafting
3. Full and effective participation and inclusion in society	<ul> <li>Include information about disability awareness training for service providers</li> <li>Explain the benefits of inclusion in workplaces and particularly leadership positions</li> <li>Make sure information is included about access and inclusion in the design and planning of initiatives</li> </ul>
Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity	<ul> <li>A focus on acknowledging the diversity of people with disability</li> <li>Emphasise the importance of education about disability</li> <li>Include that attitudinal change and raising awareness encourages respect</li> </ul>
5. Equality of opportunity	<ul> <li>Provide clear definitions of equality and equity</li> <li>Make it clear that accessibility is key to creating equality of opportunity</li> <li>Include information about affirmative measures</li> </ul>
6. Accessibility	<ul> <li>Explain how Universal Design can be applied</li> <li>Emphasise that accessibility needs to be considered early in the design phase of policy, products and services</li> <li>Explain that accessibility is not just the environment but includes communication, information, attitudes and procedures</li> </ul>
7. Equality of people	<ul> <li>Include a strong focus on intersectionality</li> <li>Point out the importance of co-design with people from intersecting groups of people with disability</li> <li>Emphasise equity</li> <li>Explain cultural safety and its importance when engaging with the diversity of people with disability</li> </ul>

Principle	Feedback to consider in drafting
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities	<ul> <li>Emphasise the importance of involving children and young people in decisions that affect them</li> <li>Provide practical guidance on how to include children and young people in decision-making</li> <li>A focus on decision-makers needing to respect and value the thoughts, views and opinions of children and young people</li> </ul>

See <u>Appendix 1</u> for more information on the history and development of the Strategy's 8 principles.

## Toolkit for engaging with people with disability in evaluation

Consultation found that people wanted to see the following themes covered in the Toolkit:

- Include people with disability across all stages of the evaluation cycle and respect individual choice about involvement.
- Provide resources to help people with disability to be involved in evaluations, including supported decision-making and training.
- Offer detailed instructions on accessible communications and ways to be involved.
- Make sure feedback is gathered on evaluation processes to identify issues and future improvements.
- Understand the value of people's time and effort who participate in evaluations.
- Ensure evaluation captures the diversity of disability and intersectional groups.
- Address barriers to participation in evaluation.

Feedback provided by people for the Toolkit for engaging with people with disability in evaluation

people with disability	
Topic	Feedback to consider in drafting
Principles of best practice for involving people with disability in evaluation	Include intersectionality and highlight the importance of lived experience
	A focus on people with disability as leaders and partners in evaluation
	Ensure adequate resourcing, including time, funding, remuneration and supports
	A strong focus on Universal Design in the principles
Design phase	Develop research questions with people with disability in an inclusive and accessible manner
	Create co-research and leadership roles for people with disability
	Design the evaluation to be respectful, safe and culturally appropriate for people with disability
	Ensure people from diverse experiences are included, particularly involving targeted approaches to engage those from underrepresented groups
Implementation and analysis phase	Enable participation through accessible communication and allow appropriate timeframes
	Consultations guided, and preferably led, by people with disability such as co-facilitation and co-presentation
	<ul> <li>Actively address barriers to participation, including giving people with disability the training and skills to do evaluation</li> </ul>
	Share the outcomes and findings with people with disability, those involved, and their communities
Recommendations phase	Ensure feedback is gathered on the evaluation process itself and mechanisms are in place to apply lessons learned to future evaluations
	Ensure that evaluation results, recommendations and action plans are made available and accessible to evaluation participants to build ongoing trust

## Part A: Detailed feedback on the Guide to Applying Australia's Disability Strategy 2021–2031

## Main themes to include in the Guide to Applying Australia's Disability Strategy 2021–2031

#### The 8 Principles

To achieve the Strategy's vision, governments have committed to creating policies, programs, services and systems that reflect the 8 principles outlined in Article 3 of the UN CRPD.

Principle 1	Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
Principle 2	Non-discrimination
Principle 3	Full and effective participation and inclusion in society
Principle 4	Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
Principle 5	Equality of opportunity
Principle 6	Accessibility
Principle 7	Equality of people
Principle 8	Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

#### Consultation questions

Consultation participants were asked to consider:

- suggestions about information needed to understand the principles
- suggestions to better inform decision-makers in applying the principles
- sharing personal stories or examples relating to each principle
- · identifying instances where the principles had been used
- the length and format of the Guide
- other advice, including anything missing from the principles.

## Feedback on themes to include in the Guide to Applying Australia's Disability Strategy 2021–2031

#### The UN CRPD and legislation

Submissions recommended:

- · providing links to the UN CRPD and relevant legislation within the Guide
- that the overlapping nature of the principles must be acknowledged (for example, principle 5 says people should be given equal opportunities, which is connected to the same idea in principle 7, which says people should be treated equally).

#### Accessible feedback and complaint mechanisms

Several submissions suggested the Guide should clearly state that accessible feedback and complaint processes are very important to applying the principles effectively. Submissions suggested that these methods ensure people with disability can participate and are not left out of opportunities to give feedback or complaints.

It was suggested the following description of a complaint process should be used in the Guide:

'A procedure within an organisation, institution or governing authority which allows individuals to report negative experiences and problematic conduct and policy; seek individual rectification; and, where appropriate, trigger system change.'

(Children and Young People with Disability Australia)

#### Disability competency and responsiveness training

The targeted focus groups found the need for disability awareness training for staff working in the public arena to be included in the Guide.

Across principles 2, 3 and 8, stories from the targeted focus groups highlighted a lack of disability awareness and skill across all sectors and all types of initiatives. Examples given included hospitality, emergency services, health, education and transport (specifically aviation).

Submissions from the Australian Government suggested these broad prompting questions could be considered:

- Is an appropriately skilled workforce available to support the proposed policy/program/service/system?
- · What capacity building activities are needed?

#### **Equity**

Many submissions recommended the principles focus on equity instead of equality or asked that the Guide outline the difference between them.

#### Families and carers

Some submissions recommended that the Guide recognise and support the contribution of family, siblings, important relationships, carers and family advocacy.

Participants in the targeted focus groups from culturally and linguistically diverse backgrounds, including from a First Nations community, highlighted the importance of principles, evaluation processes and materials being culturally relevant. This includes understanding and recognising the role of family and community.

#### Children and young people

Targeted focus group participants agreed that the safety of children and young people with disability should be prioritised and be a focus of the Guide.

Children and young people highlighted the importance of ensuring children are included in decisions about them.

#### Self-advocacy

Submissions and targeted focus group participants found that people with disability should be encouraged to advocate for themselves. This means people can communicate their own needs, also known as self-advocacy.

#### Intersectionality

The need to address intersectionality was a strong theme in feedback in submissions and across the targeted focus groups, particularly principle 7.

Feedback suggested the Guide should include specific language around intersectionality, including how it affects decision-making and people's experiences of disrespect and discrimination. The DROs said it is important to ensure the Guide helps governments to support diverse groups of people with disability.

#### Universal and inclusive design

Universal Design is a specific part of principle 6, but it was also raised in feedback across many of the principles. For example, in response to principle 3, a participant in the targeted focus group said 'Universal Design needs to be at the heart of everything – until this happens, we will not see progress.'

## Feedback on content to help people apply Australia's Disability Strategy

Principle 1: Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons

The existing prompting questions in the Strategy to help governments, businesses and the community apply this principle were:

- Does the policy/program/service/system (proposal) allow people with disability to make their own choices in the same way as people without disability?
- Does the proposal give access to supported decision-making as needed?

Participants were asked, 'What other information do you think is needed to help people understand principle 1?'

#### What we heard

- Include supported decision-making
- Allow people enough time to make decisions
- Emphasise accessible communication
- Ensure choice and control is supported

A key issue that featured across many submissions is that context should be included around supported decision-making. This includes information about available supports.

Several submissions mentioned it is important to make sure enough time and information is given to people with disability to make informed decisions. The targeted focus groups agreed it is important that people with disability understand their rights to make their own choices about how they live their lives, known as dignity of risk. First Nations participants offered the perspective that family members are important decision-makers.

Many people found communication as a key theme, including the importance of providing accessible communication. Accessible communication options should consider how people with disability may communicate consent and their decisions in different ways.

The Australian Government highlighted that guidance should be offered to organisations and the community to make sure choice and control is supported.

Submissions said information should be clear and culturally sensitive. For example, it is important to note that for many people in remote areas, including First Nations people with disability, the decision-making process is likely to be made by a group of people and not just by one person.

'Within society, negative stereotypes and misconceptions frequently prevail that a communication difficulty is synonymous with a loss of capacity and competence. This misconception can be dangerous, as many people are denied opportunities...'

(Speech Pathology Australia Submission)

'I found in my experience when other people have tried to make decisions for me, they've often made things worse for me just because they don't fully understand all of my disabilities and the impacts. So that's a really, really important one for me.'

(Targeted focus group)

#### More prompting question suggestions

- How does your policy/program/strategy help the person with disability to exercise self-determination, choice and control?
- Does the organisation have measures in place to provide education on the different ways people can request consent and provide consent?
- Is the person with disability respected as the expert-knower of their own condition and needs?

#### **Title**

The title of this principle follows the exact wording of Article 3(a) of the UN CRPD. There was one suggestion in the targeted focus groups to shorten the title to 'Dignity and self-determination.'

#### Principle 2: Non-discrimination

The existing prompting questions to help governments, businesses and the community apply this principle were:

- Does the proposal avoid both direct and indirect discrimination?
- Are reasonable adjustments available that meet the needs of each individual, so people with disability can exercise the same rights and freedoms as other Australians?
- Is the proposal compliant with the Commonwealth *Disability Discrimination Act 1992*, the UN CRPD and with state and territory anti-discrimination legislation?

Participants were asked, 'What other information do you think is needed to help people understand principle 2?'

#### What we heard

- Ensure messaging makes it clear that discrimination is prohibited
- Explain what discrimination is
- Include information on education to prevent discrimination

All engagement activities supported clear examples on direct and indirect discrimination. Some submissions suggested that language about avoiding discrimination in the Strategy is not strong enough. Submissions also said all organisations should make people aware that discrimination is prohibited.

Many submissions emphasised that excerpts from the Commonwealth *Disability Discrimination Act 1992*, the UN CRPD, state and territory anti-discrimination legislation should be included.

Submissions suggested a focus on workplaces and reasonable accommodations and attitudes within the education system. It was recommended to list reasonable adjustments that are available thematically (for example physical, environmental, neurological) and how these reasonable adjustments can be applied.

Targeted focus groups heard that mechanisms of change need to be easier to access and implement. They also emphasised that community education on disability and anti-discrimination is necessary and must start from childhood. Participants said they experienced discrimination both on individual and institutional levels. They also said awareness and education is imperative across society, including all institutions and employers. Participants from a First Nations community described discrimination in terms of feeling unsafe and needing more support workers, education about disability for family and community and more help 'out bush' aside from family.

'I had to go to [regional city] to do some training for work and I was with another lady who is in a powered wheelchair and 2 other staff members. In this situation, she organised to have [wheelchair] measurements, requirements to give to Qantas before time. However, when we got to [the destination], they couldn't get her powered wheelchair off the plane, despite telling them the requirements and other things that she needs. They gave her a manual wheelchair which was totally unsuitable for her and she ended up flying back to [where she departed] the next morning, with her support worker.'

(Targeted focus group)

'I think people advertise jobs and they say that they don't discriminate, that the job is "disability-friendly", whatever that means, or that people with disabilities can apply, or they try and make reasonable adjustment, which is not always reasonable. So, I think the employment sector has a lot to answer for, and I think, "Thank goodness for COVID, because it meant that for me, I was able to work from home, which made a big difference to my work, you know, my work/life balance.'

(Targeted focus group)

#### Suggested prompting questions

- Does the proposal ensure discrimination, both direct and indirect, does not occur?
- What systems do you have in place to prevent discrimination from occurring?
- Does the proposal empower and promote the inclusion of all people with disability, taking into account the impacts of intersectionality?
- How does the proposal address the intersecting layers of individual and structural discrimination experienced by cohorts?
- Does the proposal comply with other federal anti-discrimination tools, such as the Commonwealth Disability Standards for Education 2005?

#### Title

A suggested change to this title was 'Equality and non-discrimination' as submitted by the academic roundtable. Although the current title reflects the exact wording in Article 3(b) of the UN CRPD, it is not consistent with Article 5 entitled 'Equality and non-discrimination'.

The plain English title 'people should be safe from discrimination' was not supported by targeted focus groups as this language was not considered strong enough.

#### Principle 3: Full and effective participation and inclusion in society

The existing questions to help governments, businesses and the community apply this principle were:

- Will the proposal support people to fulfil their potential?
- Will the proposal provide for a person's inclusion and participation in all aspects of community life?

Participants were asked, 'What other information do you think is needed to help people understand principle 3?'

#### What we heard

- Include information about disability awareness training
- Articulate the benefits of inclusion in workplaces and particularly leadership positions
- Make sure information is included about access and inclusion in the design and planning of initiatives

The targeted focus groups suggested there be more included on the benefits of full and active inclusion, rather than mostly costs or challenges. They said organisations should be doing more to support greater accessibility and measures to support the inclusion of people with disability. They highlighted that people with disability have individual requirements that must be recognised, rather than having generic responses. Targeted focus group participants said disability awareness training is needed for all staff working with the public.

Various submissions suggested the inclusion of people with lived experience of disability in workplaces and leadership positions needs development.

The targeted focus groups stressed that for measures to be effective they need to be made public, and there should be consequences where access and inclusion is not provided. Targeted focus groups stressed that access and inclusion must be considered in the design and planning stages, not as an afterthought.

'I think this is really well reflected in the introduction of scholarships for people with disability at university and university residences – this is really something that helped me afford university as I can't work at the same level as my peers to pay rent. It's also key that [young people with disability] are involved moving forward with codesigning services that are targeted towards them.'

(Targeted focus group)

'The way I walk, the first assumption is "You're drunk, you have to leave, you can't have service, you're not allowed in". If we are going to dream big, any staff member that's forward facing, dealing with the public in other words, should do some level of disability awareness training.'

(Targeted focus group)

#### Changes to prompting questions

Several submissions (including the academic roundtable) objected to the term 'fulfill their potential' in the first prompting question. They suggested changes to be more personcentred, including 'self-defined potential.'

A suggested question was: 'Does the proposal recognise and harness the individual capabilities of the person with disability?'.'iii

#### **Title**

The current title is the exact title from Article 3(c) of the UN CRPD. A suggested change to this title to better align with the social model of disability was: 'Society enables full and effective participation or inclusion of all people.'

The proposed plain English version of the title 'People with disability should have the same rights as anyone else to take part in the community' was not supported by targeted focus groups as the language was considered not strong enough.

## Principle 4: Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity

The existing prompting question to help governments, businesses and the community apply this principle was:

 Does the proposal respect and recognise the equal value, worth and dignity of all people with disability?

Participants were asked, 'What other information do you think is needed to help people understand principle 4?'

#### What we heard

- Focus on acknowledging the diversity of people with disability
- Emphasise the importance of education about disability
- Include that attitudinal change and raising awareness encourages respect

Several submissions touched on the importance of acknowledging the diversity of people with disability.

The targeted focus groups noted that positive representation is important for encouraging respect. Other submissions talked about the need for more disability education in society, including inclusive places and anti-discrimination.

The importance of teaching social and human rights models of disability in education was emphasised as a part of celebrating diversity and positive changes.

The targeted focus groups emphasised that awareness raising initiatives should promote humanity and citizenship to increase respect towards people with disability amongst the general population.:

'When you greet someone with a disability, greet them the same way you would greet anyone else. Speak to the person the way you would like to be spoken to. Talk directly to the person, not their caregiver.'

(Targeted focus group)

'I would like to see all hospital staff, doctors, nurses and surgery people to be trained in disability awareness; it should be mandatory. Teach them everything, all disabilities, especially communication and respect.'

(Targeted focus group)

'People with intellectual disability often find it harder than other disability groups to have our say. The disability sector and other groups need to be educated and made to include people with intellectual disability.'

(Targeted focus group)

#### Changes to prompting questions

Changes to the prompting questions were recommended by various submissions, including questions about understanding of diversity and how initiatives are tested by people with disability.

#### **Title**

The current wording is an exact repetition of Article 3(d) of the UN CRPD. Suggested changes to this title included:

- Respect for difference and understanding of people with disability
- Respect for difference and valuing of people with varying abilities as part of human diversity and humanity.

Several submissions suggested changes, with some recommending removing the word 'acceptance' and replacing it with the word 'understanding' to strengthen the principle.

#### Principle 5: Equality of opportunity

The existing prompting questions to help governments, businesses and the community apply this principle were:

- Does the proposal provide for people (including people facing multiple forms of discrimination) to be treated fairly, including by taking positive actions to accommodate differences?
- Are there any barriers or processes in the proposal that unfairly limit people with disability from achieving their goals?

Participants were asked, 'What other information do you think is needed to help people understand principle 5?'

#### What we heard

- Provide clear definitions of equality and equity
- Make it clear that accessibility is key to creating equality of opportunity
- Include information about affirmative measures

Many submissions highlighted the importance of making sure clear definitions of equality and equity are included. They also said resourcing is important to make sure places and information are accessible for everyone, and this should happen on time. This ensures people with disability have equal opportunity to share ideas.

Submissions noted information should include special measures (positive discrimination) to help governments and businesses to promote equal opportunities.

Participants in the targeted focus groups emphasised co-design is important to support equal opportunity. They shared examples of individual and structural barriers, including in regional areas. They said that equal opportunity is important in identity building. Participants in a First Nations community reported a range of experiences including sometimes being forgotten or excluded as a barrier to accessing opportunities.

'I think the job market is something pivotal here that reflects the lack of equal opportunity – we need to provide further opportunities for [young people with disability] to be confident and capable to advocate for themselves and understand how the workforce operates.'

(Targeted focus group)

'L' related his experience about equality of opportunity in employment being systemically denied at the point of the job interview. When L, as a candidate, presents himself as an older person in a wheelchair, he feels instantly dismissed without being given the opportunity to show his capacity to do the job. This situation is made harder in rural settings as prospective employers, as well as being fewer in number, often have inaccessible premises.

(Targeted focus group)

#### **Changes to prompting questions**

Suggestions to add or change prompting questions included:

- changing the language in the first prompting question to come from a more positive angle
- changing the second prompting question to 'What barriers or processes might the proposal contain that unfairly limit people with disability from achieving their goals?
- removing the word 'unfairly' to focus on the barrier rather than the principle of equality
- focusing the principle on the giving of the opportunity rather than achievement of goals.

More questions were suggested about how proposals account for connecting or intersectional identities impacting need, and how disability diagnosis and lack of access to the medical system is a factor in unequal opportunities.

#### **Title**

The current title reflects the exact wording in Article 3(e) of the UN CRPD. One submission suggested changing the title to 'Equity of outcomes', and others wanted more emphasis on outcomes than opportunities.

#### Principle 6: Accessibility

The existing prompting questions to help governments, businesses and the community apply this principle were:

- Can people with disability access all aspects of the proposal, including the information, technology, services and location?
- Have the principles of Universal Design been applied?

Participants were asked, 'What other information do you think is needed to help people understand principle 6?'

#### What we heard

- Explain how Universal Design can be applied
- Emphasise that accessibility needs to be considered early in the design phase of policy, products and services
- Explain that accessibility is not just the environment but includes communication, information, attitudes and procedures

Submissions recommended explaining that accessibility is not the same for all people but is a range of standardised features that should apply to everyone. This should include addressing that individuals have specific accessibility needs.

"... Assume for disability rather than approaching it as needing to do something different. The message is clear. Improved accessibility benefits everyone."

(Centre for Disability Research and Policy, University of Sydney)

Submissions highlighted that accessibility is not just about physical places but includes communication, information, attitudes and procedures. Participants in targeted focus groups were in favour of including information on safe and accessible communication.

Submissions highlighted the need for policy makers to ask about accessibility requirements in the design stages of initiatives, but that accessibility also needed to be carried through to implementation and evaluation stages. Information about supports available to help with access should also be included (such as the National Relay Service). One submission suggested that consequences for breaches of access be included.

Participants from regional and remote areas also raised there are more physical barriers in these areas due to the age of infrastructure and lack of planning.

Participants in targeted focus groups emphasised that not all disability is visible, and the importance of access is for everyone, including people with invisible or undiagnosed disability.

'K' said there was an unfair pressure applied to people with disability to provide their own solutions to access problems such as bringing ramps to allow them to enter premises.

(Targeted focus group)

'Barriers to access and inclusion lead to disengagement and social isolation, reducing the chances of a person finding valued roles and building meaningful connections. What may seem like a small obstacle when considered in isolation, may actually be just one of many barriers a person must overcome throughout their day, leading to a compounding effect of discouragement and exhaustion.'

(Purple Orange)

Submissions strongly agreed with a focus on Universal Design, including the adoption of the UN CRPD definition.

Many submissions asked that the Guide explain Universal Design, and that 'smart design' increases accessibility for all. Submissions recommended addressing how Universal Design applies to services. One submission highlighted that Universal Design should not replace the need for feedback from people with disability on accessibility.<sup>iv</sup>

#### Changes to prompting questions

Suggestions to add or change prompting questions included:

- Can people with disability from different backgrounds access all aspects of the proposal?
- Including a question about how initiatives are tested with people with disability.
- Have you put in place a process for people with a disability to reach out to discuss their accessibility requirements?
- Have you included in the proposal alternative ways of communications to respond?
- Have you considered the right funding for accessibility?
- Have the principles of social model of disability been applied?
- Have the principles of best practice co-design, co-production and co-evaluation been applied?
- Has a cultural safety lens been applied?
- How is the principle of self-determination met through this proposal?
- Have you considered communications (including allowing for contributions) in multiple formats (for example, verbal, written, videos), and ensured adequate timeframes for meaningful engagement, participation, and leadership?
- Have you considered intersectional needs? For example, what supports a parent with disability may need to be able to engage in the proposal?

#### **Title**

The current title reflects the exact wording in Article 3(f) of the UN CRPD. Several submissions (including targeted focus groups) referenced including Universal Design in the title of principle 6. 'Safe and accessible communication' or 'Communication is a human right' were suggested as separate principles by several submissions. Some submissions also addressed communication within principle 6.

Suggested changes to this title were:

- · Accessibility unencumbered by ableism
- Accessibility and Universal Design
- Accessibility for all, including inclusive environments and Universal Design.

#### Principle 7: Equality of people

The existing prompting questions to help governments, businesses and the community apply this principle were:

- Does the proposal support the full development, advancement, empowerment, and equality of all people irrespective of differences and identities, including in relation to gender, age, sexuality, race, or cultural background?
- Has consideration been given to ensure policies/programs/services/systems are culturally safe and appropriate?

Participants were asked, 'What other information do you think is needed to help people understand principle 7?'

#### What we heard

- Include a strong focus on intersectionality
- Point out the importance of co-design with people from intersecting groups of people with disability
- Emphasise equity
- Explain cultural safety and its importance when engaging with the diversity of people with disability

Many submissions and the targeted focus groups outlined the importance of addressing intersectionality and to highlight key groups.

Submissions and the targeted focus groups recommended explaining the negative impacts when intersectionality does not occur. For example, a targeted service may support a person's disability but not their cultural background, which in turn effects their inclusion in the community. Submissions and targeted focus groups suggested to include explaining

what 'cultural safety' involves and stress the importance of cultural knowledge and sensitivity training for service providers.

Submissions outlined the importance of consultation and co-design with people with disability from intersectional groups. They also emphasised the importance of disability confidence training for service providers.

Targeted focus groups highlighted that equity should be emphasised for intersectional groups.

Young people in the targeted focus groups said that diversity should be seen as a strength, saying that they felt there was diverse representation of disability, identity and intersectionality more broadly within their focus group.

'Aboriginal people with disability are 100% needing to make more inclusive and equal, as they have twice as many barriers that society has, not only for their disability but for being Aboriginal as well. We need more equality for all diversity of people with disabilities.'

(Participant in People with Disability WA's survey)

'The adverse outcomes experienced by people of intersecting identities, I think ought to be explicitly acknowledged, especially since there are the current anti-discrimination laws that make it very difficult for people to raise discrimination complaints on the basis of multiple intersecting protected attributes.'

(Targeted focus group member)

#### Changes to prompting questions

Suggestions to add or change prompting questions included:

- How will you create a safe, inclusive, accessible and brave space for diverse people with disabilities to engage at every stage of the proposal?
- How can we create safe spaces where people feel comfortable to disclose their specific identity?
- Does the proposal consider how to engage with people with complex and diverse disabilities, including by taking positive actions for inclusion and accessibility?
- How can this proposal embrace and celebrate diversity, including in relation to gender, age, sexuality, race, or cultural background, to support the full development, advancement, empowerment and equality of all people as defined by themselves?
- In what ways has the cultural safety and appropriateness of the proposal been considered?
- What tools can be used to identify potential risks around cultural safety?
- How can governments, businesses and individuals better understand potential triggers and sensitivities?

- What ensures definitions related to equality, such as cultural safety and appropriateness, are working in proposals?
- Does the proposal recognise the inherent value of diversity in the human, social and cultural development of our society?
- Has consideration been given to the specific differences and barriers people with diverse gender or sexuality experience and are steps taken to overcome these challenges?

An added suggested question for principle 4 may also sit under this principle: 'What process has been used to ensure the proposal, and all its associated communications are free of ableist language and concepts and demonstrate an understanding of intersectional identities?'

#### **Title**

The current title does not reflect Article 3(g) of the UN CRPD 'Equality between men and women.' The change to 'Equality of people' in the Strategy was based on feedback the department received during consultations about ADS to be more gender inclusive.

The targeted focus groups suggested including the word 'intersectionality' in the title of this principle. Some participants noted the title of the principle did not resonate well with them as they found it confusing.

Suggested changes to this title included:

- Equality of people, including an acknowledgement of their lived experience and an upholding of intersectionality
- Equality of people, including a respect and upholding of intersectionality.

Principle 8: Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

The existing prompting questions to help governments, businesses and the community apply this principle were:

- Are children with disability being treated equally to children without disability?
- Is the best interest of the child a primary consideration?
- Are children with disability being given the opportunity to take part in decisions based on their age and maturity, and on an equal basis with other children?
- Do children with disability have access to appropriate supports to make or take part in making decisions?

Participants were asked, 'What other information do you think is needed to help people understand principle 8?'

#### What we heard

- Emphasise the importance of involving children and young people in decisions that affect them
- Offer practical guidance on how to include children and young people in decision-making
- Focus on decision-makers needing to respect and valuing the thoughts, views and opinions of children and young people

Many submissions highlighted that proposals affecting children and young people with disability should be developed in consultation with them. Practical, specific guidance and materials should be included to allow participation and decision-making.

Children and Young People with Disability Australia (CYDA) highlighted that it is essential that any proposals or initiatives affecting children align with the National Principles for Child Safe Organisations.

CYDA highlighted that a key part of ensuring children's safety is to implement the second National Child Safe Organisations principle titled 'Children and young people are informed about their rights, participate in decisions affecting them and are taken seriously'.

Targeted focus groups with children and young people highlighted:

- the importance of supports in the transition from school to adult life
- more importance should be put on children and young people being involved in their own life, decision-making about their goals, being able to self-advocate by themselves (if possible) and having autonomy
- young people's views, thoughts and opinions need to be valued and respected in all settings, especially by those in positions of power and key decision-makers within governments, organisations and the community.

Other targeted focus groups and submissions highlighted:

- respect for the needs of parents and carers of children with disability
- children with disability having the opportunity to attend mainstream (non-segregated) schools
- the importance of celebration and recognition of people with disability in school curricula.

'I think a lot of children with their parents and advocates are struggling to find what they need and how they are going to apply that within schools.'

(Targeted focus group)

'This is a really interesting principle. I find that there is a large jump of a lack of support especially between high school and adult life. If we aren't guided through how to advocate for ourselves over the years, and we don't learn what to expect then it's really rather difficult. I would say that the role of mentors and role models here are key and that we need to continue elevating stories on how to navigate this transition.'

(Targeted focus group)

'I think the only thing I would add in it is that especially children have the opportunity to advocate for themselves [...] I think it's really important that we respect kids with disability but also give them the opportunity to grow into their disability because we do have to grow up a bit differently to the rest of the world.'

(CYDA)

#### **Changes to prompting questions**

Feedback included that the first and third prompting questions be reframed to include that adjustments are needed for equal treatment or 'equitable treatment'.

Other suggested questions were:

- How are children with disability being supported and included to ensure that they can take part and be engaged on an equal basis to their peers without disability?
- Have reasonable adjustments for children with disability been considered in the proposed policy/program/service/system?
- In what ways has the proposal been co-designed with children and young people with disability and their families and carers to design a range of appropriate supports, accommodations, and safety methods to ensure accessibility and participation?
- What supports have been made for children and young people with disability to take part without relying on their primary carer?
- How have the best interests of the child been determined and framed as a primary consideration?

#### **Title**

The current title reflects Article 3(h) of the UN CRPD. There were arguments made in the targeted focus groups with children and young people that the title includes the word 'young people'. The targeted focus groups with children and young people did not support the plain English title 'Children should be treated with respect as they grow older', arguing that it was not fully inclusive and implied respect was earned.

Suggested changes to the title included:

- Respect for the evolving capacities of children with disabilities and respect for the right of children [to] preserve, develop and explore their identity, culture and personhood unencumbered by ableism
- Disabled people of all ages should be treated with respect and have their personal autonomy protected.

#### More feedback

## Title of the Guide to Applying Australia's Disability Strategy 2021–2031

Feedback showed the title 'Guide to the Guiding Principles' is confusing due to the repetition, and that it does not reflect that the purpose of the document which is to assist people to apply the Strategy's principles.

One suggested title was the 'Guide to Apply the Strategy's Guiding Principles'.

Following this feedback, the department has chosen a working title of a 'Guide to Applying Australia's Disability Strategy' and will use this title through the early development phase, subject to further review and feedback from stakeholders.

#### Titles of specific principles

During the engagement activities, participants suggested a range of changes to the titles of specific principles. This paper notes specific changes suggested in the above section under each principle. The consultation documents did not specifically ask for suggestions about titles.

As all governments in Australia agreed to the titles of the principles in the Strategy, these changes would be subject to the reviews of the Strategy itself.

#### More principles

Three more principles were suggested in response to a question in the consultation paper:

- Accessible and safe communication
- Communication
- Accessible digital communication
- Accessible digital communication technologies/digital inclusion
- A principle about 'systems that collaborate.

As all governments in Australia agreed to the principles included in the Strategy, these changes would be subject to the reviews of the Strategy itself.

#### Language

Many submissions highlighted the need for anti-ableist language, with some submissions noting that the language used in the consultation paper was 'framed around disability impairment and not ability.' \(^{\text{V}}\)

Some contributors preferred the use of 'different abilities' rather than 'disability.'vi

Many submissions also highlighted the importance of short and deliberate language, particularly in plain English and Easy Read, and importance of cohesive principles. VII

Some targeted focus group participants noted unnecessary overlap and duplication in the principles and concern about language not being appropriately accessible. VIII

#### Case studies and examples

Participants across multiple consultation activities said that it is important to use practical examples, case studies and stories for different settings.

Some submissions advocated for examples and definitions in the body of the document for context.

#### Prompting questions

Participants recommended changing open-ended questions that show how the principles apply to using action-based language.

Many submissions suggested more questions to be included. Submissions pointed out that prompting questions throughout the Guide should address engagement of people with disability.

#### **Definitions**

Submissions recommended providing clear definitions of all terms. It was also suggested that different disability experiences (For example, sensory, physical, intellectual, non-verbal, neurodiversity) should be described.

#### Length and usability

A few submissions noted that the Guide should be short. Others suggested providing links for more information or having the Guide consist of a series of fact sheets. Many noted that the Guide should be more practical than theoretical.

#### Recommendations included:

- clearly broken up sections with examples and diagrams
- providing checklists and planners to help drafters in applying the principles
- making the Guide accessible in a multitude of ways and formats, including creative formats and multi-media, and making sure these are distribution friendly
- · establishing ongoing communities of practice
- making sure users can seek expert advice/independent phone advice about how to apply the principles to a specific proposal.

#### Transparency and accountability

The targeted focus groups noted they would like to see more information about transparency and accountability from governments, organisations and other community groups about applying the principles. This included reporting statistics and improvements.

#### Other suggestions included:

- a complaint mechanism that includes regular review and feedback mechanisms
- the use of the principles in government processes such as regulatory impact statements
- resources to help in the application of the principles, for example, an independent advisory service so legal obligations are understood
- specific resources for decision-makers to include children and young people with disability in decision-making
- consideration of a scorecard or assessment tool, rating how well the principles have been applied.

# Application of the principles when there are short decision timeframes

One submission said that short timeframes for development and implementation of policies/programs/services/systems must never be used as reason for not adhering to the full implementation and adherence to the principles. ix

Another submission said that the Strategy Guide should make it clear that short timeframes are not conducive to full and equal participation. ×

# Part B: Detailed feedback on the Toolkit for engaging with people with disability in evaluation

#### The importance of evaluation

Evaluation is critical to knowing what is working well and what needs improvement for people with disability. The Toolkit will help governments, businesses and the community ensure people with disability are involved in evaluating policies, programs, and services.

The Toolkit will support governments' commitments to evaluation and build on the Strategy's Evaluation Good Practice Guide Checklist.

The proposed best practice principles for evaluation set out in this consultation are sourced from the United Nations research protocols and recent work produced in Australia on inclusive research practices. They are designed to underpin an ethical and respectful approach to evaluations with people with disability.

#### **Consultation questions**

Participants were asked to consider and provide feedback about:

- the proposed best practice principles for evaluation
- possible additional principles
- each phase of the evaluation cycle
- what should be included in the Guide to ensure people with disability are actively involved across all stages of the evaluation cycle.

#### Overarching feedback

Submissions and participants in the engagement activities recommended:

- the Toolkit include instructions on accessible communications throughout, including consideration of communication differences for people with intellectual disability and accessible formats
- a feedback mechanism for evaluation to identify where there were issues and provide future improvements
- actively involving people with disability across all stages of the evaluation cycle, and making sure there is respect for individual choice on whether people with disability would like to be involved and what elements they would like to be involved in

- ensuring training is provided to people with disability to ensure they have the skills to take part in evaluations
- acknowledging the importance of recognition and payment for people with disability who participate in evaluations. Some participants raised the importance of offering options for payment, such as vouchers, to avoid impacting pensions
- ensuring that there are sufficient resources to involve people with disability in evaluations
- the evaluation principles capture the diversity of disability
- the Guide actively addresses barriers to participation in evaluation. The need to include advocates and carers was raised in relation to supported decision-making.

'We want to be included; we want to be part of decision-making... We know we don't always have the resources to do that on top of everything else that we're trying to do as part of our funding, particularly if we get an additional consultation or an additional opportunity... And the other side of the two-edge sword is that people with disability, yes, we are experts. And yes, we know our needs better than anyone in terms of accessibility, but it doesn't mean we're always across-the-board access experts.'

(Centre for Disability Research and Policy, University of Sydney)

# Feedback about best practice for involving people with disability in evaluation

In the consultation documentation the department proposed 9 principles of best practice for involving people with disability in evaluation and requested feedback across consultations and in submissions. The principles proposed were:

- **1. Informed and transparent** Decisions and processes about evaluation are open and transparent and led or informed by people with disability.
- **2. Promotes wellbeing** The evaluation contributes to the wellbeing of people with disability.
- **3.** Co-design Co-production, collaboration and joint decision-making with people with disability are embedded throughout the evaluation process.
- **4. Co-researchers** In addition to involving researchers and academics with disability, people with disability outside of academic or research institutions are included as active co-researchers (also known as participatory or community researchers).
- **5. Relevance** Evaluations explore issues important to people with disability.
- **6.** Accessible The evaluation process is accessible to people with disability.
- 7. Diversity The evaluation process includes people with disability across a range of experiences. For example, cultural groups, gender, sexuality, ages, and geographical location.

- **8. Ownership** People with disability have a degree of ownership over evaluation design, implementation, dissemination, and actions flowing from recommendations.
- **9. Co-presentation** People with disability are included in the presentation of evaluation findings.

#### What we heard

- Include intersectionality and highlight the importance of lived experience
- Focus on people with disability as leaders and partners in evaluation
- Ensure adequate resources, including time, funding, remuneration and supports
- Have a strong focus on Universal Design in the principles

Submissions and participants in engagement activities highlighted the importance of the following:

- intersectionality and highlighting lived experience of diverse groups of people with disability. It was emphasised that this should acknowledge that disability is diverse
- people with disability being leaders and partners in evaluation
- ensuring enough resources, including time, funding, remuneration and supports
- including a stronger focus on Universal Design in the principles.

Following consultations with children and young people with disability, one organisation suggested reframing the principles and their title to better reflect the expertise and lived experience of people with disability. The suggested title was, 'Best practice principles for partnering with people with disability in evaluation.'

#### Feedback about the proposed phases of evaluation

#### Design phase

The design phase of evaluations includes selection of the type of evaluation (process, impact or summative), the research questions and methodology. The Toolkit will set out how to actively involve people with disability in the design phase to bring in their lived experience and knowledge. This could include:

- identifying, consulting and promoting consultation with appropriate stakeholders in a variety of ways in an inclusive and accessible manner
- developing research questions with people with disability, so the evaluation focuses on issues important to people with disability
- establishing co-researcher and leadership roles for people with disability

- designing the evaluation to be respectful and safe for people with disability. This
  includes gaining informed consent and using trauma-informed approaches with
  robust feedback and complaints procedures
- considering how the needs and views of both diverse and specific groups are part of the evaluation design.
- designing the evaluation to have culturally appropriate representation and safety as core components
- adopting flexible methods that are appropriate to people from various groups and ages, such as people with intellectual disability, First Nations people, people from multicultural communities, people who are LGBTIQA+ and people from rural, regional and remote communities.

#### What we heard

- Develop research questions with people with disability in an inclusive and accessible manner
- Create co-research and leadership roles for people with disability
- Design the evaluation to be respectful, safe and culturally appropriate for people with disability
- Ensure people from diverse experiences are included, particularly involving targeted approaches to engage those from underrepresented groups

Submissions and participants identified several key issues across consultations, particularly around ensuring inclusivity in the design phase.

Academic roundtable participants highlighted that the design phase begins before the project, such as when designing the tender, and that people with disability should be involved from this early stage.

Several submissions highlighted the importance of ensuring people from diverse experiences are included, particularly involving targeted approaches to engage those from underrepresented groups.

One submission emphasised the importance of accountability and ensuring independent governance processes.

People with intellectual disability in the targeted focus groups spoke about the importance of planning small group sizes so everyone feels comfortable and can have a say. People said the ideal group size depended on the purpose, but agreed 5 to 6 people was ideal, with more being too many.

'The design phase must also consider outreach strategies that could help facilitate the participation of cohorts who are typically underrepresented in consultation processes, such as children and young people with disability, people with psychosocial disability and people with disability who are digitally excluded.'

(Australian Federation of Disability Organisations)

'I think being mindful of the language used, especially for youth, evaluations can seem very formal, we want to avoid alienating any age groups.' (Targeted focus group)

'People with disability are the key stakeholders of disability policy and programs.

People with lived experience therefore need to be central to evaluating the performances of these programs and in decisions regarding future policy directions.

Policy does not finish with evaluation but rather is a "continually turning wheel".

Hence, people with disability need to be actively and genuinely included in all policy phases from issues identification onwards.'

(Centre for Disability Research and Policy, University of Sydney)

#### Implementation and analysis phase

The implementation and analysis phase of evaluations includes subject recruitment, data collection and interpretation, and sharing results. The Toolkit will set out how to actively involve people with disability in the implementation phase. This could include:

- making it easy for people with disability to participate through accessible communication about the evaluation. This includes allocating appropriate time and resources using accessible materials and formats. It also includes providing appropriate engagement approaches for intersectional groups, including cultural safety and relevance for all ages
- consultations being guided by people with disability, such as co-facilitation by people with lived experience of disability
- adopting Universal Design methods for data collection. This means having flexible and accessible approaches to support people with different types of disability and circumstances. This also includes Indigenous Data Sovereignty and Data Governance principles
- respecting the time and effort of people with disability, including consideration of remuneration and incentives
- actively addressing barriers to participate in the evaluation
- capturing broken down data to give visibility on the impacts for people with disability with different backgrounds, situations and experiences
- producing evaluation findings in a way that supports translation into real life improvements for people with disability
- providing opportunities for people with disability to co-present evaluation findings
- sharing the outcomes and findings with people with disability, including people directly involved, as well as the broader disability community.

#### What we heard

- Enable participation through accessible communication and allow appropriate time
- Make sure consultations are guided, and preferably led, by people with disability such as through co-facilitation and co-presentation
- Actively address barriers to participation, including giving people with disability the training and skills to do evaluation
- Share the outcomes and findings with people with disability, those involved, and their communities

Ensuring participation and leadership by people with disability was a key issue raised across consultations on this phase. Participants across consultation activities also recommended:

- ensuring people with disability were leaders and partners in this evaluation stage, involved in the interpretation and able to put the findings into context
- outsourcing evaluations to organisations run by people with disability that have experience in evaluation and incorporating opportunities for people with disability to take on leadership roles in evaluation
- actively addressing barriers to participating in this phase of evaluation, including giving people with disability the training and skills to do evaluation
- ensuring there are opportunities for continuous feedback built into the process to enable changes as the initiative progresses
- including a clear commitment to making the findings of evaluations public.

'Barriers to participation (and the solutions) need to be identified by people with disability.'

(Brightwater submission)

'B' noted that it was important to have people with disability conducting the evaluation in places around the country in diverse regional centres.

(Targeted focus group)

'It's crucial that there are trauma informed people with some level of lived experience acting as facilitators for focus groups, consultations and events such as this one, rather than bureaucrats or policy makers who can't facilitate the same organic and open-minded conversation with vulnerable communities.'

(Targeted focus group)

#### Recommendations phase

The actions flowing from recommendations is the final phase of evaluation. This phase covers the actions taken and responses given to the findings of the evaluation. The Toolkit will set out how to actively involve people with disability in actions flowing from the recommendation phase. This will depend on why the evaluation is being done. For example, to understand the need for a government program or activity, identify good practice, improve design and performance, determine impacts or inform decisions about future policy development.

For this phase, the Toolkit focuses on setting out approaches that can be used to actively engage with people with disability in the application of the findings. This could include:

- recognising the expertise of people with disability in providing guidance on how to apply findings to policies, programs, services and systems
- advising on the planned process to determine how evaluation findings will be considered
- providing opportunities, including enough time and forums to consider or plan action from the evaluation.

#### What we heard

- Ensure feedback is gathered on the evaluation process itself and mechanisms are in place to apply lessons learned to future evaluations
- Ensure that evaluation results, recommendations and action plans are made available and accessible to evaluation participants to build ongoing trust

Communication, accessibility, and representation were some of the key themes raised in consultations on this phase.

- Several submissions highlighted the importance of ensuring the results are made publicly available in a range of accessible formats.
- Participants told us about the importance of highlighting that evaluations are cyclical, so it is important to work through lessons learned to lead to future improvements.
- The targeted focus groups recommended ensuring ongoing communication with stakeholders, including by providing timely and clear information for people involved in the evaluations and all community members.

- Participating academics suggested including reflective practice to lead to future improvements (considering lessons learned and applying these when planning future evaluations) and incorporating a mechanism to validate that co-design has occurred.
- The targeted focus groups recommended making lived experience of disability a key selection criterion for those in charge of the evaluation and making recommendations for initiatives that relate to inclusion of people with disability so that outcomes reflect the diversity of people's needs.

'It could be useful to explicitly state that evaluation findings can in turn feed into the next iteration of a co-design process for the development of new, or strengthening of current, policies, programs and systems.'

(National Legal Aid)

'...Making sure these evaluations are actually used for something practical, are implemented (with proof back to the community) and not done as lip service.'

(Targeted focus group member)

'S' said she thought it was important for regional and rural people to be included in the presentation of results in-person. Even if this means a lot of money needs to be spent on airfares and accommodation as doing things via Zoom is ineffective at getting people to understand your disability and its implications.

(Targeted focus group)

## **Glossary**

Table 1: Glossary

Term	Meaning
Auslan	Auslan is Australian sign language. Auslan is used by Australians who are deaf or hearing impaired, and by people communicating with them. It's a visual form of communication that uses hand, arm and body movements to convey meaning.
Braille	Braille is a form of written language for blind people, in which characters are represented by patterns of raised dots and are felt with the fingertips.
CALD	Culturally and linguistically diverse.
Co-design	Co-design is a design process where stakeholders are equal partners and take leadership roles in the design of products, services, systems, policies, laws and research.
Co-facilitation	Co-facilitation is when people with disability partner in leadership and engagement.
Co-production	Co-production is when researchers and people work together through all stages of research. This includes the planning and doing stages.
CYDA	Children and Young People with Disability Australia. CYDA is a DRO.
DANA	Disability Advocacy Network Australia. DANA is a DRO.
DDA	The <u>Disability Discrimination Act 1992</u> (DDA) is national legislation that makes discrimination because of disability unlawful in a broad range of areas of public life. This includes education, and access to premises, goods, services and facilities.
The department	Australian Government Department of Social Services and Department of Health, Disability and Ageing
DRO	<u>Disability Representative Organisations</u> (DROs) provide systemic advocacy and representation for people with disability. They also provide advice to the Australian Government on breaking down barriers and improving participation of people with disability.

Term	Meaning
Easy Read	Easy Read is a way to present information for people who are not familiar with English, or who have low literacy or learning disability.
The Guide	The Guide to Applying Australia's Disability Strategy 2021–2031.
Intersectionality	Intersectionality recognises that a person or group of people can be affected by multiple forms of discrimination and disadvantage due to their race, sex, gender identity, sexual orientation, impairment, class, religion, age, social origin, and other identity markers.
NDIS	National Disability Insurance Scheme.
QDN	Queensland Disability Network.
Targeted focus groups	These were specific harder to reach intersectional groups of people who attended workshops run by Disability Representative Organisations and facilitated by DANA.
The Strategy	Australia's Disability Strategy 2021–2031 (the Strategy) is Australia's national disability policy framework. It is driving action at all levels of government to improve the lives of people with disability. The Strategy launched on 3 December 2021.
The Toolkit	The Toolkit for engaging with people with Disability in evaluation.
UN CRPD	The United Nations Convention on the Rights of Persons with Disabilities (the UN CRPD) is an international human rights convention which sets out the fundamental human rights of people with disability. Its purpose is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.
Universal Design	This means ensuring that as much as possible, environments, products and services can be used by all people, without the need for adjustments.

### **Appendix 1**

# Background to the development of Australia's Disability Strategy 2021–2031 principles

#### Principles of the National Disability Strategy 2010–2020

The UN CRPD Article 3 general principles were the principles of the *National Disability Strategy 2010–2020*. xi These were:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- · Equality of opportunity
- Accessibility
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

# What did people say about the principles in the development of Australia's Disability Strategy 2021–2031?

#### Stage 1 consultations - April to July 2019

The first consultation report about the Stage 1 consultation in 2019 did not address new principles. Xii However, many people said there needed to be a stronger focus on the implementation of the UN CRPD in Australia. People said Australia could do much more to include the UN CRPD in policy and legislation, promoting and protecting the rights of people with disability. Xiii

#### Stage 2 consultations – July to December 2020

The National Disability Strategy Position Paper (the Position Paper).xiv released in July 2020 suggested and sought feedback on further principles in addition to those based on Article 3:

- Involve and engage.
- Design universally.
- Engage the broader community.
- Address barriers faced by priority populations.
- Support carers and supporters.

In response to Stage 1 feedback, the Position Paper.<sup>xv</sup> provided an overview of the proposed structure of the new Strategy including:

- strong support for alignment with, and reference to, the UN CRPD principles
- varied enhancements to the proposed principles including reporting and accountability methods
- some new principles
- a view that additional principles were duplications of the general principles in the UN CRPD.

In the Report on Targeted Workshops.xvi participants suggested:

- the focus of principles should be on ensuring respect, equality, inclusion, accessibility, independence, compassion and support within the Strategy and associated policies, actions and programs included consideration of intersectional identities
- people with disability must be heard and involved in all aspects of the Strategy to have a greater voice in public policy
- more open communication
- highlighting the importance of Universal Design and accessibility
- reflect progress toward the social model of disability
- the Strategy needs to carefully consider and prioritise different intersections for people with disability in the community.

#### The current principles of Australia's Disability Strategy 2021–2031

The current Strategy principles were developed based on feedback from the consultation process for the development of the Strategy including from state and territory governments. The principles were agreed by all governments and mirror Article 3 of the UN CRPD except for principle 7 'Equality of people'. The UN CRPD Article 3(g) wording 'equality between men and women' was changed to 'equality of people' in the Strategy. This was based on feedback the department received during consultation to be more gender inclusive and prioritise different intersections for people with disability in the community. 'Equality of people' embraces the full development, advancement, empowerment and equality of all people irrespective of differences and identities, including gender, age, sexuality, race or cultural background, while also having a focus on equality between men and women.

### **Appendix 2**

#### Participation in the public consultation

#### Public written submissions from organisations

Submissions about the Guide were received from individuals and the following organisations:

- Action for More Independence and Dignity in Accommodation
- Advanced Care Planning Australia
- Australian Communications Consumer Action Network
- Australian Federation of Disability Organisations
- Carers NSW
- Centre for Disability Research and Policy (University of Sydney)
- CYDA
- Dementia Australia
- Early Childhood Intervention Australia Victoria/Tasmania
- Family Advocacy
- National Aboriginal Community Controlled Health Organisations
- National Legal Aid
- People with Disabilities WA
- Pharmaceutical Society of Australia
- Physical Disability Council of NSW
- Professionals and Researchers in Early Childhood Intervention
- Public Advocate QLD
- Purple Orange
- QDN
- Reimagine Australia
- Siblings Australia
- Speech Pathology Australia.

Submissions about developing an Toolkit were from the following organisations:

- Australian Federation of Disability Organisations
- Brightwater
- Centre for Disability Research and Policy (University of Sydney)
- CYDA
- Dementia Australia
- National Legal Aid
- People with Disabilities WA
- Pharmaceutical Society of Australia
- Public Advocate QLD
- Purple Orange
- QDN
- Reimagine Australia
- Women with Disabilities Australia.

#### Academic institutions at roundtable discussions

Representation at the roundtable on the Guide held 18 November 2022:

- Deakin University
- Griffith University
- Monash University
- Queensland University of Technology
- University of Melbourne
- University of Queensland
- University of Tasmania.

Representation at the roundtable on the Toolkit held 26 October 2022:

- Independent Advisory Council,
- NDIS
- Australian National University
- Flinders University
- La Trobe University
- University of Melbourne

- University of New South Wales
- University of Sydney
- University of Technology Sydney.

The Centre for Disability Research and Policy (University of Sydney) made a separate public submission after conducting a survey and workshop consultations on the Guides. These consultations involved 21 people: 6 authors and 15 stakeholders, including people with lived experience of disability.

#### Disability Representative Organisations group sessions

The department facilitated 2 workshops with ADS DRO Implementation Working Group.

The DRO group session on the Guide was held on 28 October 2022. DRO representatives were:

- Australian Federation of Disability Organisations
- Brain Injury Australia
- CYDA
- Deaf Australia
- Down Syndrome Australia
- Inclusion Australia
- National Ethnic Disability Alliance
- People with Disability Australia.

The DRO group session on the Toolkit was held 20 October 2022. DRO representatives were:

- Australian Federation of Disability Organisations
- Brain Injury Australia
- CYDA
- Disability Advocacy Network Australia
- Down Syndrome Australia
- Inclusion Australia
- National Ethnic Disability Alliance
- People With Disability Australia
- Physical Disability Australia.

#### DANA focus groups

The Department funded DANA to work with DROs or state-based alternatives to run targeted focus groups with a diverse range of people with disability to inform the Guides.

The participating DROs were:

- CYDA
- Down Syndrome Australia
- Inclusion Australia
- National Ethnic Disability Alliance
- Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council
- Physical Disability Australia
- Physical Disability Council of New South Wales.

From the targeted focus groups, the DROs received insights, examples and stories to inform the Guides from people with disability.

The DRO held a total of 16 targeted focus groups engaging with a total of 111 people with disability between November 2022 and June 2023. Each focus group went for approximately 1.5 hours.

Each DRO focused on engaging with a particular cohort of people with disability and aimed to engage key intersectional and harder to reach groups. This included young people, xvii people with intellectual disability, people from culturally and linguistically diverse (CALD) communities, First Nations peoples, people from rural and remote areas, and people with diverse disability. Physical Disability Council of New South Wales ran a second round of focus groups in June 2023 for women only.

#### Focus group demographics

People with disability engaged in the focus groups included:

- a range of people with disability, including intellectual disability, cognitive impairment, physical disability, neurodiversity, psychosocial disability and sensory disability
- people aged from 15 years to over 65 years
- women, men, transgender and gender diverse people with approximately 75% of young people in the groups facilitated by CYDA identifying as part of the LGBTQIA+ community, and 25% of participants identifying as trans and gender diverse
- people from every state and territory in Australia, including regional, rural, remote and very remote locations

- people identifying as First Nations (representing approximately 20% of the total number of focus group participants) with most from the Ngaanyatjarra Pitjantjatjara Yankunytjatjara Lands (Anangu) and individuals from Victoria and New South Wales
- people with different cultural backgrounds, including Anglo-European, South and Central Asian, Southeast Asian, South and Central American, Caribbean, Australian, North African and Middle Eastern, Sub-Saharan African and Nepalese
- people speaking a range of languages including English, Maltese, Korean, Hindi, Marathi, Tamil, Punjabi, Swahili, Arabic and Urdu.

#### Methodologies

Each DRO adjusted their engagement approach to suit the people with disability involved. These approaches included:

- 5 of the 7 participating DROs engaged with most of the same people when discussing the Guide and the Toolkit. This in-line with good practice in engagement methods as it enables facilitators and groups to get to know each other and build rapport
- Down Syndrome Australia held one focus group on the Guide only
- Inclusion Australia held one focus group on the Toolkit only
- some DRO organisations adjusted the consultation materials, so they were more relevant to the cohort they work with. This included adaptations for young people (CYDA), First Nations peoples (Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council) and people with intellectual disability (Inclusion Australia)
- working with smaller groups of people with disability.

Each DRO ensured their focus groups were relevant and accessible to people with disability. Access needs of participants included:

- information in Easy Read, adapted for young people and people with intellectual disability
- translation into community languages for Anangu people with disability
- captioning
- questions and materials sent in advance of the focus group
- materials in certain contrasts
- materials in plain language
- taking breaks during sessions
- using a range of communication methods such as verbal, text, chat, and Augmentative and Alternative Communication (AAC) devices.

Each DRO worked in a trauma-informed way. Approaches included:

- inviting people to share stories and being sensitive to the risk of re-traumatising
- providing content warnings about topics being discussed
- making referrals to appropriate organisations when disclosures of abuse occurred.

### **Appendix 3**

#### Promotion of consultation activities

#### The Department of Social Services communication channels

Promotion material was included:

- on Carer Gateway's Facebook page
- on the International Day of People with Disability Australia's Facebook page
- on Disability Gateway's Facebook page
- on the department's website
- in a Disability Gateway article.

#### External communication channels

Promotion material was included:

- on the NDIA's LinkedIn page
- on the NDIS's Facebook page
- on the NDIS' X page previously called 'Twitter'
- on the NDIS' Instagram page
- in an NDIS e-newsletter
- in a Services Australia news article.



#### **Endnotes**

<sup>1</sup> Language translations were in Arabic, Chinese Simplified, Chinese Traditional, Filipino (Tagalog), French, Greek, Hindi, Italian, Korean, Macedonian, Samoan, Spanish, Vietnamese.

ii The Centre for Disability Research and Policy (University of Sydney)

iii Centre for Disability and Policy (University of Sydney)

iv Physical Disability Council NSW

<sup>&</sup>lt;sup>v</sup> Centre for Disability (University of Sydney) and DANA Report

vi Centre for Disability (University of Sydney) and DANA Report

vii Centre for Disability (University of Sydney) and DANA Report

viii Centre for Disability (University of Sydney) and DANA Report

ix The Australian Communications Consumer Action Network

<sup>\*</sup> The National Legal Aid

xi Commonwealth of Australia (2011). National Disability Strategy 2010–2020, p. 22.

xii The Social Deck (2019). Right to Opportunity: Consultation report to help shape the next national disability strategy.

The Social Deck (2019). Right to Opportunity: Consultation report to help shape the next national disability strategy.

xiv The Department of Social Services (2020). National Disability Strategy Position Paper July 2020.

<sup>&</sup>lt;sup>xv</sup> The Department of Social Services (2020). National Disability Strategy Position Paper July 2020.

xvi The Social Deck (2021). Stage 2 consultations: Report on Targeted Workshops April 2021.

xvii CYDA represent children and young people aged from 0-25 years.

