



Submission to Australia's Disability Strategy 2021-2031: Consultation to inform the Strategy Guides

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Thank you for the opportunity to respond to the Australia's Disability Strategy 2021-2031: Consultation to inform the Strategy Guides.

We wish to make comments on the *Guide to apply the Strategy's Guiding Principles* and section two on the *Guide to Involve People with Disability in Evaluation*. These comments have been informed through Centre for Disability Research and Policy (CDRP) survey and workshop consultations with stakeholders including people with lived experience of disability.

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Guide to Apply the Strategy's Guiding Principles

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

There is a need to **explicitly value the experiences of people with disability**. A key question becomes, "is the person with disability respected as the expert-knower of their own condition and needs?" Such questioning is empowering as it places the person with disability at the center of all decisions about their lives.

Professionals can at times defer to formal and informal supports rather than talking directly with the person with disability. This is disrespectful. Decision-making should always start with the person with disability rather than deferring to other people or assuming other people. The person with disability will always be the first choice for making that decision.

For some people with disability, the freedom to make one's choices can require that particular supports be in place. Alternative communication options need to be provided to ensure people with disability have the opportunity to participate in decisions about their life and not have them made by the people around them. For example, provision of Auslan interpreters, availability of communication boards in hospitals/ police stations /schools, having information provided in Easy Read format.



The dignity, autonomy and freedom of people with disability can be undermined by various ableist actions and social conditions. These include restrictive practices as applied by service providers and a lack of affordable housing that can see people with disability experiencing homelessness or living in places such as boarding homes where they are exploited. It is essential to take the time for supported decision making.

Consultation does require some time to be also factored in, not only for accessible communication but also for briefing and bringing people up to date on where things are at. Ensuring people with disability have appropriate opportunities and support to make choices. Taking the time to discuss options to ensure the person has full understanding and accessibility rather than limited or outdated options.

It is necessary for there to be genuine choice and control afforded to people with disability, with great care taken to ensure any supports that are offered are not patronising and do not guide choices through the lens of what a non-disabled person thinks is best. Above all, people need to feel they are being listened to and genuinely understood.

Principle 2: Non-discrimination

Language about 'avoiding discrimination' in the Strategy is not strong enough. The Strategy needs to highlight that discrimination (both direct and indirect) against people with disability is unacceptable and should use stronger language to promote this message. The first prompting question of the guide should be: *"Does the proposal ensure discrimination, both direct and indirect" does not occur?"*



There also needs to be **active compliance and enforcement of anti-discrimination legislation**. With this in mind, greater efforts and resources are needed to stop discrimination from happening against people with disability in the first place. A cultural shift is required.

There should be explicit illustrations with excerpts from the Disability Discrimination Act 1992, the UN CRPD, and state and territory anti-discrimination legislation, as many people will not be aware of or will not have read these documents.

Workplaces should not discriminate against employees with disability by denying reasonable accommodations. Delays in providing reasonable accommodations, because of inadequate funding, resourcing, or staffing, should be considered as discrimination under the anti-discrimination act. Adjustments should be provided in a timely manner so that delays don't create further barriers and distress. For this to be successful, adjustments must have been budgeted for appropriately. A significant lack of investments and lack of funding for people with disability shows a lack of respect.

There is also a need to focus on the education system in order to redress the discrimination that is experienced by students with disability who encounter teachers that believe they do not belong in mainstream schools. Teachers require education about disability and reasonable accommodations, together with the benefits of inclusive education. Attitudes about children with disability being difficult or naughty require change. There needs to be **more disability education throughout Australian society** to advance inclusive places. Continuing with an "othering" of people with disability by



presenting them in negative ways only serves to perpetuate stereotypes and encourages further discrimination.

Principle 3: Full and effective participation and inclusion in society

There needs to be a greater acknowledgment and emphasis on the benefits that come from inclusion rather than highlighting the costs or challenges to enabling inclusion. We would like you to consider rewording the prompting questions to recognise every person's individual capability rather than the broad term of full potential "Does the proposal recognise and harness the individual capabilities of the person with disability?"

There also needs to be a shift so that disability accommodations are seen as investments or "smart spends" rather than as burdens for companies and for society- – that cost is being balanced by the benefits of inclusion and lived experience.

An inclusive Australia requires a shift away from policy shortfalls as reflected in shameful unemployment rates for people with disability that have barely changed over two decades. Change towards a more inclusive Australia is needed now.

One place this starts is in the workplace. It starts with promoting employment of people with lived experience of disability in policy-making teams, in academic research teams, and for practical application, in service provider teams. So, the benefit of lived experience can come through in supporting more people with disability. Increasing presence and



participation of people with disability in workplaces. People with disability who wish to participate in paid employment should be supported to achieve that goal.

Australia needs to have more leaders with disability across governments and corporate organisations. Jordon Steele-John and Dylan Alcott are good examples - but there needs to be an increase in diverse representation of women with disability, people with disability from migrant and refugee or First Nations communities.

Inclusive workplaces are fair workplaces. Employers need to pay people commensurately for their lived experience expertise, qualifications and abilities and not expect to consult with them for free as a token "disability representative". There is also a need to pay people in Disability Enterprise organisations a proper wage and not undervalue their work. Australians with disability deserve to be valued and not exploited.

For people with disability to retain employment, workplaces must be accessible. Examples include considerations of sensory needs, providing information in a variety of formats such as screen reader accessible and Easy Read. Disability audits of workplaces need to be compulsory. Also, there is a need to change building codes so that accessibility requirements are mandatory in all states.



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

The wording of this principle is ableist and offensive as it implies that in some instances, a person with disability is or has not been considered as part of humanity! This principle needs to be reworded to recognise the wide range of abilities that compose human diversity, rather than emphasising a dichotomy between able and disable. "Acceptance" is NOT a strong enough word - the message needs to be around "valuing" and "elevating". The focus should be on "ability" and "contributions". There is a need to enforce the use of inclusive language and to respect diversity and difference. Valuing the different perspectives, different knowledge and experiences. We encourage to stop talking about disability and start talking about different abilities and range of varying abilities.

We strongly suggest rewording this principle as follow:

"respect for difference and valuing of persons with varying abilities as part of human diversity and humanity"

Normalising disability is fundamental to greater understanding and acceptance. For some in the community, disability can still be seen as a scary or dangerous thing. Until these negative attitudes are openly challenged, nothing will change. This means educating at an early level about differences and acceptance of all. There needs to be a change in school curriculums so that diversity and difference is celebrated and not shamed. Teach the social and human rights model. The lack of respect for people with disability is entrenched in our school system and continues to shape peoples' ongoing attitudes towards disability throughout their lives. This cycle of ableism needs to be broken.



Principle 5: Equality of opportunity

Policymakers need to recognise the **role played by delays in meeting disability accessibility requirements**. In order to ensure equality of opportunity, communication is needed, and communication requires time. In some instances, more time is needed depending on the population addressed. Time is required to use a variety of accessible communications as well as to brief people to allow them informed access to potential opportunities.

Equal opportunity means providing the necessary funding for disability accessibility requirements needs to be met. Such resourcing should be seen as an essential investment for the betterment of the society. Concerning employment, there needs to be clear targets/quotas to ensure that people with disability get greater access to employment opportunities. These targets need to be closely monitored with corrective actions taken wherever necessary.

Principle 6: Accessibility

As the general population doesn't understand the wide range of disability access needs, the **Guide needs to be explicit about what accessibility is**. It is important to acknowledge that access for some will be a barrier for others. For example, night lighting is a barrier for those with contrast and glare sensitivity. There are **no one-size fits all accessibility solution**, but there is a range of basic standard accessibility features that should be applied more widely. These include systematic live captioning of videos, systematic image description (ALT text) in documents and webpages, choice of



big fonts, high contrast settings, checking compatibility with text reader etc. Where these do not adequately address accessibility a dialogue with the person with disability or the group of people with disability is essential to define their specific accessibility needs. It should be noted that you cannot put “fully accessible” into policy as this is unfeasible.

Additional prompting questions may be:

- “Have you put in place a process for people with a disability to reach out to discuss their accessibility requirements? Hotline, email address, a survey of accessibility requirements etc...”
- “Have you considered appropriate funding for accessibility?”
- “Have you included in the proposal alternative way of communications to respond? E.g. drawing, picture, photo, video, audio recording etc...”

When thinking about **Universal design**, it is about “smart design”, rather than making something accessible for people with disability. It is increasing accessibility for all. For example, disabled toilets are just “well-designed” toilets.

Care is also needed not to solely focus on physical accessibility. Accessibility is also informational, attitudinal and procedural. There is a need to implement programs and training to address attitudinal and behavioural discrimination towards and against people with disability. These programs and training must be created and presented by people with disability themselves and not by some “professional expert”. There is a need to embed accessibility into policies and procedures in schools and workplaces. Assume for disability



rather than approaching it as needing to do something different. The message is clear. **Improved accessibility benefits everyone.**

Principle 7: Equality of people

Australia requires **improved opportunities for students with disability to succeed** in the school system through an adaption of the curriculum, availability of reasonable adjustments, and the changing of attitudinal bias among teachers through teacher training. Also, there needs to be far more people with disability in positions of power and leadership roles to shape the culture of organisations towards greater inclusion. Equity is further advanced by employing more people with disability and paying them for their abilities and lived experience expertise.

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

Within the education system, there should be child inclusion in the planning and review meetings to establish individual goals. For example, in the school setting via Personal Learning Support Plans (PLSP) and with therapists including Occupational and Speech. Every student should be acknowledged for their strengths and capabilities. This fundamental value should be taught to teachers when they are training.



Additional questions

Question 9: Is there anything missing from the Guiding Principles that should be included in the Guide? For example, are there any other guiding principles you think should be added and why?

Comments

There's a **missing principle about "Communication"**

Communication is a human right- all human beings should be given a way and the means to communicate in a way that suits their abilities. The assumption should be made that every person has a way of communicating and they can hear everything that's being said.

Prompting question could be:

"Have you included several ways of communication to give a voice to all, according to their own abilities"?

The language used throughout **the guide is framed around disability impairment and not ability**. The tone and positioning of the document start from a negative appraisal rather than respect and valuing appraisal. The language used in the guide should be modified to acknowledge people's abilities rather than acknowledging their disability and working with people to maximize that ability, shifting from a negative appraisal to a valuing perspective of the contribution of people with disability.

There is a need for a fundamental investment in better systems and better outcomes for people with disability to be able to operationalise the Strategy and apply the guiding principles.



Question 10: Do you have any good examples of when the Guiding Principles have been used?

Comments

As a group we encourage you to **stop talking about disability and start talk about different abilities** and a range of varying abilities.

An example taken from one of our CDRP Members who attended our consultation:

"I'm assistant principal at a special needs school. I work with from K to 12 children with disabilities. And I particularly teach a group of young students with autism at the moment. But within the school, there are many students with physical disabilities and medical conditions and things.

For my students with autism to try and understand that, I constantly just refer to the other students and say, "Yeah, there are some people here who do not walk as well as you, who do not talk as well as you, do not hear as well as you, do not speak as well as you, do not think as well as you. It doesn't mean they have a disability, and it doesn't mean the students with autism have a disability. We all just might not do things the same as somebody else ... it is a school where everybody, every student has a disability, but we don't talk about it as a disability. It's just you might not do this as well or you might need this to be able to do something the same as somebody else."

"In my class, I also bring in a student who uses a communication device. And so, now my students have learned to help her use the eye gaze because they've modelled that. They will just say, "Oh, you can answer. Tell me on there."



Gone is the barrier. Gone is that she doesn't talk ... she doesn't use her words, but she still communicates. Communicating and talking, just in a different way.”

This is a good example because of the language used, the demonstration of a different way of communicating successfully, and the adoption of a different way of communicating by all the students (not only the student with speech impairment) but also because of the funding that supported the student in using a new way of communication through new equipment and the funding and time put into training the other students in using it.

Question 11: What length and format should the Guide be so that it is easy to apply? For example, should it be a series of fact sheets with supporting videos?

This guide needs to be more practical than theoretical. Good and practical examples of inclusion and accessibility need to be provided in multiple ways to show how the principles can be applied well, with a wide range of examples of inclusive practices and accessibility features. All information should be accessible with a variety of ways to engage including facts sheets, videos, podcasts, live Q and A sessions, ongoing discussion boards, and an associated community of practice.



Guide to Involving People with Disability in Evaluations

Proposed Best Practice Principles for Evaluation

The guideline fails to offer advice in terms of how to practically apply the principles (e.g., how to reach out to people with disability and genuinely involve them in co-design, how to accommodate accessibility requirements, how to remunerate people with disability for their participation in evaluation).

We note a **key missing principle: 'LEADERSHIP'**. Lived-experience leadership and not only co-design should be the model adopted for evaluating disability policy and programs. People with disability are the experts on their own accessibility needs and should lead evaluation work related to it. It is ableist to suggest that for any evaluation work about disability, there is no person with lived experience capable of taking on a leadership role. People with lived experience should be considered as the decision-makers. The currently proposed principles fail to recognise and value disability leadership and need to change. The language in the guide should use "led by and with people with disability" rather than "co-designed" as a way to empower people with disability, strengthen their voice, and elevate their lived expertise. Where additional technical knowledge is needed, we suggest projects to be led by people with disability in collaboration with "expert allies".

We recognise a second **missing principle: 'INVESTMENT'**. Investment in training, support for accessibility requirements and accommodations, investments in true lived-experience-led evaluation projects, investment in training lived-experience



leaders, investments in thorough consultation with people with lived expertise. These are the types of investments that are needed for a better society. A society that values diversity and inclusion.

Specific gaps

- **Principle C. Co-design.** Fails to recognise people with disability as holding leadership roles in the evaluation process (i.e., disability-led evaluations).
- **Principle F. Accessible needs** to be expanded to *accessible and accommodating*. i.e., accessible to and accommodating of people with disability.
- **Principle G. Diversity** - does not mention different types of disability.
- **Principle H. Ownership** - states that 'people with disability have a degree of ownership'. What degree? Who decides? This statement fails to recognise and value leaders with lived experience. The statement also does not acknowledge an ongoing and unethical dominance of non-disabled policymakers in the disability policy space.
- **Principle I. Co-presentation.** Need to acknowledge that some people with disability will need communication accommodations in their presentation of evaluation findings. Also to what extent are people with disability included? Again, there are persisting gaps in terms of valuing and respecting disability leadership.



‘Nothing about us without us’ applies to best practice principles for evaluation (i.e., that the principles about best practice for involving people with disability in evaluation are proposed and ultimately decided upon by people with lived experience). To what degree are policymakers prepared to apply this disability inclusion mantra in a review of the Guide’s current principles?

Design phase

Included in the design of evaluations for disability policy, programs and services needs to be budgeting for disability inclusion. Specifically, appropriate budgeting for the organisation of consultation, appropriate remuneration of participants with disability and accessibility costs, and the recruitment of people with lived-experience as project leaders. There is currently nothing explicit in the guide about accommodating people with lived experience in the design phase.

Implementation and analysis phase

The statement of “consideration of remuneration” for people with disability is ableist and needs to be replaced with “consistently and fairly remunerate people with disability”. Incentives (i.e., gifts) should also be fair in value and financially commensurate with the work completed. To do otherwise is to exploit people with lived experience. People with disability need to be recognised as the expert knowers and remunerated accordingly. Costs of accommodations need to be seen as investments in conducting best practice evaluations.

The Guide also needs to recognise that consultations can be *led by* people with disability and to clearly state how to actively



address barriers to participating in evaluations (e.g., by redressing ableism and providing accommodations). The Guide must be explicit on what is needed.

Actions phase

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'¹. Hence, people with disability need to be actively and genuinely included in all policy phases from issues identification onwards.

Other advice

RESOURCING STRATEGY for NGOs and DPOs involved in the consultation process- We would like to raise a need to build the capacity of DPOs and DROs to employ people and have the funding to be involved in more evaluation. This calls for the recruitment of people with lived-expertise within these organisations who have an interest in evaluation, or in developing evaluation methodologies and approaches, et cetera, and who are supported to develop their skills in that way.

Quote from a researcher participating in one of our workshop: "as researchers, we want to work with NGOs and disabled people's organizations, but often we're taking their time away. So it's almost like there's not enough time for that essential role in the sector to do its job in supporting their disability

¹ Bridgeman, P., & Davis, G. (2004) The Australian Policy Handbook



strategy. So if you have written into it that we need to co-produce things, we need to be involving the sector in everything, we can't just be taking time away from the sector all the time.

We need to better resource the NGO and the DPO sector to do that essential job. It can't just be that they have more and more and more and more that they have to do because otherwise, it gets depleted and exhausted and people can't get access to the enormous knowledge that the sector has. So it has to be resourced in a sensible way that really values the integral nature of the knowledge in the sector.... it just needs better resourcing of that system.”

Quote from a coordinator in an advocacy organisation for people with disability: “I guess it's a two-edged sword. 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 probably better than anyone in terms of accessibility, but it doesn't mean we're always across-the-board access experts. And there are so many times people come to me in the work I do and I have accessibility in my job title and all that. Asking me, "How do we make our online platform accessible?" And these are highly technical things. Whilst we can engage in that area of work, again, it's very resource intensive.”



REMUNERATION

the guide needs to include remuneration guidelines for people with lived-experience involved in evaluation. Being involved in an evaluation as a lived-experience expert should be remunerated as a job – recruitment of lived-experience leader should be part of the process.

RECOGNITION OF LIVED-EXPERTISE in the evaluation work can be done fairly through remuneration, co-authorship, paid position as researchers/ research officer/ lived-experience expert. People with lived-expertise need to be recognised for their true value, the real expertise they are bringing to a project, as consultants and not only participants.

CONCLUSION

The guide only makes one brief mention about disability-led evaluation processes. There needs to be far greater focus on and valuing of disability-led activities throughout the guide. Crucially, a guide that fails to fill in this gap is open to strong public criticisms of ableism from disability advocates and their genuine allies.