CYDA's response to the consultation papers for Australia's Disability Strategy: *A Guide to the Guiding Principles and A Guide to involving people with disability in evaluation*

"The framing of the principles was very much with the disabled people as bystanders as opposed to being key stakeholders in the evaluation process". Consultation participant, November 2022

⚠️ **Content note: Discussion of ableism**

Children and Young People with Disability Australia

December 2022

Contents

CYDA's submission to DSS on Guides for Australia's Disability Strategy

Executive summary and recommendations

As a representative organisation for children and young people with disability across Australia, CYDA views the supplementary materials to Australia's Disability Strategy as a critical component of delivering the vision of the strategy along with fulfilling our own purpose to ensure governments, communities and families, are empowering children and young people with disability to fully exercise their rights and aspirations.

In the context of evidence demonstrating the additional ways that children and young people with disability are oppressed and marginalised due to their age and legal status, and drawing on data gathered from young people with disability, CYDA recommends the following.

Recommendations: A Guide to the Guiding Principles:
1. The Guide as a whole should,
    a. ensure an anti-ableist framing
    b. be subject to a regular review process leading to continuous improvement
    c. contain a built-in feedback and complaint mechanism
    d. provide relevant examples and case-studies co-designed by people with disability
    e. provide resources specific to children and young people co-designed by this cohort
    f. acknowledge the overlap in ideas and concepts across the principles.
2. Change prompts from closed questions to exploratory, open-ended questions that encourage deeper reflection and engagement with the principles.
3. Include mechanisms to address the unequal power dynamic that people with disability, especially children and young people, often experience
4. Create opportunities for advocacy, including self-advocacy
5. Ensure every person involved in the delivery of proposals is enabled to act in accordance with the principles
6. Address and improve existing inequity, risk and disadvantage.
7. Provide clearer and fuller definitions of terms throughout the document
8. Consult with children and young people on all issues that impact them and be guided by the National Principles for Child Safe Organisations[1].

Recommendations: A Guide to involving people with disability in evaluation:
The Guide should:
1. Foreground the expertise and lived experience of people with disability
2. Use co-design as an overarching aim of evaluation
3. Re-prioritise and define in more detail the principles of evaluation
4. Provide supplementary information on investment to support co-design opportunities
5. Ensure all phases of evaluation:
    a. Provide accessibility
    b. Include young people and use diverse channels for diverse perspective
    c. Develop processes for ensuring consultations are facilitated in ways that are anti-ableist and trauma informed
    d. Compensate people for their expertise and lived experience
    e. Share the impact of people's contributions with them.

---

[1] https://childsafe.humanrights.gov.au/national-principles

CYDA's submission to DSS on Guides for Australia's Disability Strategy

1. Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA has an extensive national membership of more than 5,000 young people with disability, families and caregivers of children with disability, and advocacy and community organisations.

Our vision is that children and young people with disability are valued and living empowered lives with equality of opportunity; and our purpose is to ensure governments, communities, and families, are empowering children and young people with disability to fully exercise their rights and aspirations. We do this by:

- Driving inclusion

- Creating equitable life pathways and opportunities

- Leading change in community attitudes and aspirations

- Supporting young people to take control

- Calling out discrimination, abuse, and neglect.

CYDA welcomes the opportunity to contribute to the Department of Social Services' (DSS) Consultation to inform the Strategy Guides for Australia's Disability Strategy:

1. A Guide to the Guiding Principles
2. A Guide to involving people with disability in evaluation

Our submission draws from data collected by CYDA. Two consultation sessions, co-facilitated by young people with disability, were run with the express purpose to gather feedback from young people with disability on the topic of the Australian Disability Strategy guide (The Guide). Two 90-minute online sessions were held on 24th and 29th November 2022 with 17 young people with disability attending. Young people were asked to provide feedback and give opinions and examples based on the list of principles and the elements of evaluation. Additional data was also collected from some participants who chose to provide feedback in writing.

Some ideas and data were also gleaned from past sessions and events run by CYDA, including the National Youth Disability Summit 2020 and consultations run in conjunction with the Centre for Inclusive Design (2022) about establishing good practice guidelines for engaging with people with disability (used with permission). Quotes from these projects are labelled as such in the text. All other quotes are from the recent consultations held to inform this submission.

1.1 Context and evidence for CYDA's submission

From the earliest moments of life, children and young people with disability face intersecting discrimination from the medical and health service sector, educational systems, government support services, and the community. A meta-analysis of 328 studies in 2014 found that the impact of these cumulative instances of perceived discrimination, including ableism, is associated with a higher level of psychological distress and decreased wellbeing, especially

CYDA's submission to DSS on Guides for Australia's Disability Strategy

in children.[2] More recently, research has revealed increased likelihood of trauma in people with disability[3], something the Disability Royal Commission has also noted in its progress reports[4].

The fact that these experiences coincide with a significant and once in a lifetime phase of brain development and physical growth, make children particularly vulnerable to experiencing lifelong negative impacts from discrimination and exclusion.

Systemic change is necessary to ensure children and young people are granted the same opportunities as their non-disabled peers, as they transition through critical developmental and life stages. Across many systems, we are failing to provide equitable and effective support. The most recent data on this cohort tells us:

- Young people with disability are twice as likely to be unemployed as their same aged peers without disability and three times more likely than people with disability in the 25–64-year-old age group[5].
- Students with disability leave school before the age of 16 at a rate nearly three times higher than their counterparts[6] and are less likely to complete year 12 or attain a tertiary education, such as a gaining a bachelor's degree or higher[7].
- More than double the proportion of the young respondents with disability in a national youth survey felt negative or very negative about the future compared to their non-disabled peers[8].
- Nearly half of young people with disability aged 15 to 24 years (49 per cent) rely on income support payments as their main source of income compared to 14 per cent of those without disability[9].
- Compared to their peers, children with disability are[10]:
  - at more than three times higher risk of physical violence
  - at nearly three times higher risk for sexual violence
  - over four times higher risk for emotional abuse and neglect.

Given these alarming figures and the problematic power dynamic children and young people are often exposed to within powerful institutions, CYDA acknowledges the critical importance of the work of Department of Social Services in supporting governments, community and businesses to engage more deeply with Australia's Disability Strategy. Not only will these resources be part of fulfilling the Strategy's vision of an inclusive Australian society that

---

[2] Schmitt, M.T. Et. Al. (2014). *The Consequences of Perceived Discrimination for Psychological Well-Being: A Meta-Analytic Review.* Psychological Bulletin, Vol 140(4), pp.921-948.

[3] Ullmann, H. Et Al. (2022). *Stressful Life Events Among Children Aged 5-17 Years by Disability Status: United States 2019*. NCHS Data Brief No. 431. Available at: https://www.cdc.gov/nchs/products/databriefs/db431.htm

[4] See 'Document Library' for progress reports https://disability.royalcommission.gov.au/document-library

[5] AIHW. (2018). *People with disability.* Available at https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/employment/unemployment

[6] 10.9 per cent of young people aged 15 to 24 have left school before the age of 16 compared to 3.6 per cent of young people without disability; AIHW. (2018). *People with disability in Australia.* Available at https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/education-and-skills/educational-attainment

[7] AIHW. (2018). *People with disability in Australia.* Available at https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/education-and-skills/educational-attainment

[8] Mission Australia. (2019). *Young, willing and able*: *Youth Survey Disability Report 2019.* Available at https://www.missionaustralia.com.au/publications/youth-survey/1610-young-willing-and-able-youth-survey-disability-report-2019/file

[9] AIHW. (2019). *People with disability in Australia: In brief.* Available at People with disability in Australia 2019: in brief (Full publication;21Aug2019Edition)(AIHW)

[10] Wayland, S & Hindmarsh, G. (2017). *Understanding safeguarding practices for children with disability when engaging with organisations.* Available at Understanding safeguarding practices for children with disability when engaging with organisations | Child Family Community Australia (aifs.gov.au)

CYDA's submission to DSS on Guides for Australia's Disability Strategy

ensures people with disability can fulfil their potential as equal members of the community, but they will also create cultural and systemic change benefitting all people with disability, including the unique cohort, children and young people with disability.

Instances where children and young people with disability do not have full and effective participation and inclusion in society and do not experience equality of opportunity, are human rights violations[11].

Institutions and organisations rarely provide young people with disability opportunities to meaningfully engage with policy and program development processes or consultation, and there is a long way to go to ensure these processes are genuinely inclusive and built on co-design principles[12]. A report CYDA commissioned in 2014 provided evidence on the many benefits stemming from the inclusion of children and young people with disability in participatory activities at the local, structural and systemic level[13]:

> *"Participation by children and young people in advocacy and change-making can not only improve and foster positive change in their own lives, but also influence the lives of others. When young people's participation is supported, meaningful and engaged, multiple benefits accrue. Their perspectives and experiences bring a unique contribution and can result in rights-based empowerment, enacted citizenship and improved relationships. This has the potential to shape policy, to increase the relevance and responsiveness of organisations they use, and to influence change in their communities in positive ways.[14]"*

However, the report noted:

> *"There are a range of barriers that discourage, prevent or actively exclude children and young people from participating. Some of these are social and cultural barriers, such as attitudes and low expectations. Others are practical — participation processes which limit the depth and involvement of children and young people's influence, such as one-off, adult-led consultations. These barriers to participation are magnified for children and young people with disability, particularly younger children and those with higher or more complex support needs.[15]"*

Ensuring children and young people are front and centre in the decisions that affect them is a key priority for CYDA. We strive to ensure children and young people are recognised as the agents and experts in their life, making informed decisions as they grow, are included in ways that are meaningful to them, and have their human rights upheld.

---

[11] United Nations. (1990) Convention on the Rights of the Child, adopted and opened for signature, ratification and accession by General Assembly resolution 44/25 of 20 November 1989 entry into force 2 September 1990, in accordance with article 49, https://www.unicef.org/child-rights-convention/convention-text

[12] "*Co-design is an inclusive, collaborative process whereby a diverse range of people with relevant skills, experience or interests come together to provide advice and make decisions on a project, policy, program or initiative*". See, Purple Orange: Guide on Co-design with People Living with Disability https://purpleorange.org.au/application/files/7416/2510/1861/PO-CoDesign_Guide-Web-Accessible.pdf

[13] Lord, J. E., Et. Al. (2012). Human Rights. Yes! Action and Advocacy on the Rights of Persons with Disabilities. In N. Flowers (Ed.), Human Rights Education Series, Topic Book 6, 2nd Edition. University of Minnesota.

[14] Simmons, C., Robinson, S. (2014) *Strengthening Participation of Children and Young People with Disability in Advocacy. Report prepared for Children and Young People with Disability Australia.* https://www.cyda.org.au/resources/details/86/strengthening-participation-of-children-and-young-people-with-disability-in-advocacy p. 5

[15] See footnote 14. Simmons, C., Robinson, S. (2014), p. 33

2. A Guide to apply the Strategy's Guiding Principles: CYDA's response

2.1 Feedback spanning all principles

Ensure anti-ableist framing

In order to be truly inclusive and anti-ableist[16] this guide must be co-designed in partnership with people with disability, including young people. Young people with disability have highlighted to CYDA that they often feel a lack of belonging in experiences where it is assumed the default human is not someone like them. For instance, a participant in CYDA's National Youth Disability Summit 2020 who identifies as an LGBTQIA+ aboriginal person with disability, explained:

> *"I felt left out. Felt different. Felt like I don't belong. Like the default is white, abled and heterosexual".*

This young person's experience reflects the commonly referred to academic definition of ableism, as follows.

> *"A network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human."[17]*

To successfully uphold Principle 4, "Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity", this guide must avoid inadvertently 'othering' people with disability and perpetuating damaging ideas of normative personhood.

> *"The norm produces violence by not allowing people to be what they desire to be at the most fundamental aspects of life; hence it is violence by restriction and negation".*[18]

To this end, CYDA recommends engaging people with disability, especially young people, in the design and review process of The Guide and it's supporting materials. CYDA also recommends that prompt questions be framed as open ended as opposed to the currently suggested questions which are closed and require only yes/no responses. Doing so encourages deeper engagement with the content, genuine consideration of tangible strategies, and prevents a tick box approach by organisations. Such an approach also ensures inclusion and accessibility become the minimum standard that organisations are working towards.

Regular review and feedback and complaints mechanisms

As with all content that aims to be useful and relevant, The Guide and it's supporting materials should be subject to regular review. Additionally, all processes and materials must recognise that people with disability, especially children and young people, are more likely to

---

16 See Cheri Byrne-Haber's nine steps to being anti-ableist https://sheribyrnehaber.medium.com/are-you-ready-to-be-anti-ableist-in-2021-239103637949
17 Campbell, F. (2001) *Inciting legal fictions: 'disability's' date with ontology and the Ableist body of the law*. Griffith Law Review 2: 42–62. Available at: https://research-repository.griffith.edu.au/handle/10072/3714
18 Campbell, F. K. (2013). *Problematizing Vulnerability: Engaging Studies in Ableism and Disability Jurisprudence*, Keynote presentation. Available at: https://documents.uow.edu.au/content/groups/public/@web/@law/@lirc/documents/doc/uow166211.pdf

CYDA's submission to DSS on Guides for Australia's Disability Strategy

be impacted by unequal power dynamics. One young person with disability participating in CYDA's consultation raised the idea of including feedback, saying:

> *"There should be a principle where individuals should have the ability to give feedback anonymously and safely. And that feedback should be recorded and taken onboard whilst the strategy is being enacted".*

CYDA recommends including supporting materials to assist organisations to develop a safe and effective feedback and complaint process to support each principle as a means of addressing this problematic dynamic. A research report commissioned to provide guidance to the Disability Royal Commission[19] describes a complaint mechanism as 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"*. This report recommends any such process should be fit for purpose, provide an equal right to justice, be integrated into other reporting pathways, be safe to use, and enable systemic change in a timely manner. Moreover, the process should acknowledge and account for the labour being performed, and the precarious position that people with disability are in when they make a complaint, namely that "complaints are more likely to be received well when they are made by those with more power"[20].

Provide examples and case studies

CYDA strongly urges the department to include examples and case studies, co-designed and produced by people with disability, as supplementary resources to The Guide. They should include examples of ableism occurring and the impact of when these principles are breached. One young person participating in a consultation highlighted the need for explanatory materials and noted that users may not have ever had experience with disability.

> *"I get confused a lot with wording. I think it's really important, especially for young people, to have written examples in the strategies, but also for able-bodied people, people following strategies to actually be able to see and read more than just fancy writing, so then they can actually put it in perspective because they don't have any experience a lot of the time to do with anything disability related or what it's like coming from the disabled person's perspective. I think it's important to prioritise that."*

Without tangible examples, the principles are at risk of becoming an optional tick box process that organisations engage with tokenistically. Grounding each principle in real world, practical examples provides organisations with the opportunity to engage in a more reflective process capable of creating sustainable and systemic change.

Create resources specific to children and young people

As a cohort that is particularly vulnerable to the power differential within organisational structures, CYDA recommends separate and specific resources be developed to ensure access and inclusion for children and young people with disability.

---

[19] Wadiwel, D. Et. Al. (2022) *Complaint mechanisms: Reporting pathways for violence, abuse, neglect and exploitation.* Available at: https://disability.royalcommission.gov.au/publications/complaint-mechanisms-reporting-pathways-violence-abuse-neglect-and-exploitation
[20] Ibid.

CYDA's submission to DSS on Guides for Australia's Disability Strategy

Acknowledge the high level and overlapping nature of the Principles

As many of the young people who participated in our consultations pointed out, the principles, their explanations and prompting questions contain many high-level and overlapping ideas. For instance, one person said, the principles should be "more specific because they are quite vague" and another thought "five and seven are basically repetitions".

CYDA recommends The Guide acknowledge this – the risk of not doing so means that organisations working with the principles may inadvertently collapse them, resulting in the reduction of their efficacy.

2.2 Comments and feedback on each principle

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

During the consultation session on these principles, one young person with disability shared an experience they had when engaging with a hotel quarantine program which could easily be an example of a 'proposal' to which this principle could be applied.

> *"I was at an airport, and it was during COVID, so everyone was going off to hotels to quarantine for two weeks. And I explained that my brother had to come and stay with me, because I couldn't bend down to pick things up, and I didn't know how well I'd do two weeks by myself without any help.*
>
> *And I'd filled out all the right forms and stuff, but they still weren't letting him come up and be with me so that we could go into quarantine together. And there was a policeman there who said, 'well, if you're sick then you should be in hospital.' And he called an ambulance and made me go through the whole process of riding in an ambulance to the hospital, even though I wasn't sick. I'm just disabled. And I was in a wheelchair, and he kept telling me to sit down. And it was awful. But yeah, that was just completely unnecessary and embarrassing, and shows a clear lack of training, I guess, in how to treat people with disabilities".*

The impact of failing to respect this young person's autonomy and dignity was clearly detrimental at the level of the individual, but such actions limit the success of the overall program (which readily exemplifies a proposal in development).

Two participants in the consultation described experiences in which they were not afforded the dignity of making the choices they felt were right for them in an educational setting.

> *"I was made to repeat a year, despite getting straight As the entire year, because I was in hospital over the end-of-year exam period. And that really, really affected me. It just made me feel like I didn't have any control. So I think a lot of people have had similar experiences, about not only university, but high school, which is just awful, because you're really young and impressionable in high school. But at least at uni I can – I know my rights a bit more, you know?"*
>
> *"I didn't have the ability to do an ATAR because I had people decide for me that I would be on a modified curriculum. For all of my high school. So I am having to play catchup now because of choices that weren't really made with my best intentions if I'm being honest. And it's been quite frustrating having to try to talk to this high prestigious university that has an expectation of certain things. Even though I know*

within myself I definitely have the capabilities of being at this university and having no problems, but the fact that they see, "Oh, modified. Oh, all this stuff. No, we're going to make you do it the hard way," even though I know I can do it easy."

Creating mechanisms that enable choice for people with disability, especially those who are additionally marginalised such as children and young people, is an essential component of any proposal.

Resources to support this principle should include the Australian Law Reform Commission's National Decision-Making Principles[21]. These principles are consistent with Australia's human rights commitments – namely, the United Nations Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child– and can provide an aligned approach across Commonwealth laws and frameworks, inclusive of responsibilities.

Moreover, building advocacy opportunities, including self-advocacy, into this principle is an essential component of creating environments where people with disability can have autonomy. One participant in this consultation shared a sentiment that was echoed by many others.

> *"There should be a principle about self-advocacy and having the right to advocate for yourself and not only have other people advocate for yourself, for you. But also having the right to get other people to advocate for you so it's not just you advocating for yourself all the time, everywhere because that's exhausting".*

Change the existing questions to:
- How does the policy/program/service/system (proposal) enable people with disability to make their own choices in the same way as people without disability?
- What strategies does the proposal contain to ensure access to supported decision-making for those who require it?

Additional prompts should include:
- What mechanisms have been put in place to ensure the proposal understands and addresses the existing power dynamics of those impacted by it, as well as any power dynamics the proposal might create?
- How does the proposal accommodate individuals who are transitioning to increasingly independent decision making (for instance, children and young people and those with intellectual disability as they gain experience and maturity)?
- How might this principle relate differently for multiple marginalised cohorts such as children and young people, first nations people, or gender diverse people with disability?
- What design aspects of the proposal will ensure that every individual involved with aspects of its delivery (including any ad hoc or peripheral personnel) will act in accordance with this principle?
- What mechanisms have been put in place to ensure individuals have an opportunity to advocate for themselves or be supported to have someone advocate for them?
- What structures are in place to listen to people with disability if they aren't experiencing individual autonomy or feel a lack of respect and dignity?

---

[21] Australian Law Reform Commission. (2014). *Equality, Capacity and Disability in Commonwealth Laws.* Available at: https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/

CYDA's submission to DSS on Guides for Australia's Disability Strategy

Principle 2: Non-discrimination

In order to best support the principle of non-discrimination, it is important that The Guide be designed in a way that enables its users to understand how people with disability are discriminated against in daily life and what the widespread impact of this is.

The young people we consulted gave us many examples of discrimination that prevent them from accessing experiences and services in daily life and from enabling their full and effective participation in the community. One young person in the consultation explained their difficulty with finding employment and their impression that indirect discrimination played a role in not being offered opportunities.

> *"But I think people's impression of me, maybe, is changed when they find out I'm disabled. And that has been quite negative. I have missed out on several job opportunities in the past, and it's really hard to prove that it's because of discrimination"*

Another shared an example of direct discrimination during the job seeking process.

> *"Back when I was in high school, I applied for a job as a Domino's worker, and they asked me questions about if I was disabled. Then I said, 'yes' and then they basically said that I can't work there because I'm disabled, because all disabled people have hygiene issues[…] I really felt discriminated against".*

These examples highlight the need for a safe complaints process, described previously in our overall recommendations, enabling more vulnerable cohorts such as young people with disability, to shape the systems and services they use.

Resources to support this principle should include specific case studies of organisations that have successfully identified and addressed direct and indirect discrimination towards people with disability. They should account for the particular ways that vulnerable groups such as children and young people are at increased risk of discrimination.

Change existing questions to:
- How has the proposal considered the ways that people with disability are commonly directly and indirectly discriminated against and what measures have been put in place to combat this?
- What reasonable adjustments are available to 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 Disability Discrimination Act 1992, the UN CRPD and with state and territory anti-discrimination legislation?

Additional prompts should include:
- What safe, fit-for-purpose and justice-based complaints mechanism does the proposal include in its design to enable continuous improvement and systemic change[22]?
- What process is in place to ensure that constant review and reflection is made to prevent discriminatory practices or behaviour outside of the complaint mechanism?

---

[22] Wadiwel, D. Et. Al., (2022). Complaint mechanisms: Reporting pathways for violence, abuse, neglect and exploitation. Available at: https://disability.royalcommission.gov.au/publications/complaint-mechanisms-reporting-pathways-violence-abuse-neglect-and-exploitation

CYDA's submission to DSS on Guides for Australia's Disability Strategy

Principle 3: Full and effective participation and inclusion in society

CYDA understands inclusion as an active process that goes beyond simply sharing the same space.

A young person from the consultation 'Good Practice Guidelines for Engagement of People with Disability' raised the idea of engaging people with disability more broadly in community life, not only in disability related processes.

> *"Actually, I'm also a parent, I own a house, I use transport, and I'm interested in politics. Don't only get people with disability to do consultations when it's about disability".*

As the following two participants highlighted, young people with disability are coming to programs and environments in the context of existing inequity. Proposals whose designers want to ensure full and effective participation and inclusion need to ensure they understand this existing risk and disadvantage, not just that which the proposal might create.

> *"Because some [people with] disabilities can't pay for – some families too can't pay some sports for the child, or – it's not fair. The fees should be for free."*

> *"My main concern is probably equity. I think that there are huge barriers in terms of the disproportionate financial concerns of disabled people. I think that the cost of living is really, really quite higher, and I think that in terms of government pension support, NDIS, they tend to be on the lower end, and kind of like an afterthought. I think that the ability to have a relatively healthy quality of life does tie into a lot of financial support, especially with independent or isolated disabled young people, who might not have those connections and communities and outreach to get the NDIS going".*

One participant highlighted the common assumption that the main support person for the person with disability will provide accommodations to enable that person access to the community.

> *"I see that a lot, where bigger organisations will put the brunt [of the] load onto the main carers, or closest supports rather than doing their part, [and] ensuring that the process is as user friendly and [puts the] least pressure on the people utilising the services".*

Resources to support this principle might include examples of peer support as peer work approaches have been shown to be effective in participation and engagement.[23]

---

[23] Greer, A. M., Et. Al. (2019). Peer engagement barriers and enablers: insights from people who use drugs in British Columbia, Canada. *Canadian Journal of Public Health: A Publication of The Canadian Public Health Association, 110*(2), 227. https://doi.org/10.17269/s41997-018-0167-x

CYDA's submission to DSS on Guides for Australia's Disability Strategy

Change existing questions to:

- In what ways does the proposal support people with disability to fulfil their self-defined potential?
- What methods does the proposal use to ensure a continuous engagement with inclusivity as defined and required by people with disability?

Additional prompts should include:

- How does the proposal plan for the changing nature of participation and inclusion (for instance as people's impairments and abilities change over time and as new methods and technologies become available to allow for increased participation)?
- How does the proposal acknowledge or attempt to alleviate organisational and societal structures which prevent full inclusion?

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

Young people with disability in CYDA's consultations demonstrated concern that this principle might not necessarily lead to respect for their differences and therefore true inclusion for them. For instance, one participant commented:

> *"I think it's all fair and good to say 'equal' but that doesn't necessarily mean that everyone's going to have the same chances to have things accessible".*

Another participant described an interaction with a medical professional who was attempting to dissuade them from applying for financial assistance based on their disability, something the young person perceived as a lack of acceptance for their disability.

> *"I've had a doctor tell me that applying for the DSP was giving up and I should just freewheel my way out of it. I should just want so much to not have so much pain and disability, that I am simply able to work more than 15 hours a week. That was really hurtful because financial independence is not giving up. It's giving me the stability I need to start working on treatments or something that's quite difficult."*

Inclusion of invisible disabilities in the diversity of disability was raised by one participant, via written feedback

> *"I think it's important that we continue to have a wider discussion on self-internalised ableism and the discrimination that people with invisible disabilities experience as not being 'disabled enough' in the eyes of the physical disability community and society at large"*

This participant also added their thoughts on how respect for diversity can be perpetuated via media representations.

> *"This principle is achieved centrally through positive representation of people with disabilities. It's important that we see [people with disability] in positions of power, I find Stella Young's TED talk[24] on this quite poignant".*

---

[24] Stella Young. (2014). *I am not your inspiration, thank you very much.* Available at: https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much?language=en

CYDA's submission to DSS on Guides for Australia's Disability Strategy

When considering how to encourage users of The Guide to show respect for disability and diversity, content should address the conscious and unconscious bias that prevents this from happening. Materials should provoke shifts in thinking through illustration of concepts such as intersectionality, ableism, and disability pride—with the co-design process generating this work.

> Change existing question to:
>
> - In what ways does the proposal demonstrate understanding of diversity and amplify a sense of equal value, worth and dignity of all people with disability?
>
> Additional prompts should include:
>
> - What process has been used to ensure the proposal and all its associated communications are free of ableist language and concepts and demonstrate and understanding of intersectional identities?
> - How does the proposal acknowledge diversity within disability such as visible, invisible and dynamic disability?
> - How does the proposal ensure that those with invisible disabilities feel comfortable in disclosing their disability if they'd like to?

Principle 5: Equality of opportunity

CYDA promotes equity and justice which allows for individual and tailored accommodations and supports for people depending on their needs and circumstances (where as 'equality' suggests providing the same accommodations and supports regardless of individual circumstances). While we are aware that the consultation document specifies this difference in the explanation table ("Equality of opportunity does not always mean that the exact same opportunities are made available to all, as treating everyone the same might result in inequalities") CYDA feels it is critical to lay this out very clearly in the documentation DSS intends to create.

The following experience shared by a young person in the consultation provides an example of a program that intended to create equity in opportunities for people to receive the COVID vaccination, but the details in its delivery suggest it didn't meet its objective in this instance.

> *"I went to get my fourth COVID vaccine and basically, I went into what's referred to as an access and sensory clinic. It's a clinic that's made for disabled people and is meant to be a safe spot for them, that's meant to not have many issues with getting the vaccine, all that kind of stuff. I have used that space three times prior to my fourth one, so they know me. It was all good, all that kind of stuff. […] I am autistic so I don't have a visible disability. What ended up happening was I went in with my dad. The nurse was asking me a bunch of questions. Didn't ask me any questions of my disability, just asked all these certain questions and because I didn't fit that criteria, I said no. Then what ended up happening was I got my vaccine. This nurse then stops me from leaving and basically makes me answer why am I here. She did that by opening up the Australian guidelines of the vaccine website, and she basically said I need you to point to what section you belong to, to basically explain why you're here. So that wasn't fun".*

Change existing questions to:
- How does the proposal provide for people (including people facing multiple forms of discrimination) to be treated fairly, including by taking proactive actions to accommodate differences?
- What barriers or processes might the proposal contain that unfairly limit people with disability from achieving their goals?

Additional prompts should include:
- How will the proposal address potentially conflicting access needs across people's intersecting identities and attributes such as disability, gender, indigeneity, cultural and linguistic diversity, and age?
- How does the proposal recognise and address the entrenched inequalities of certain multiply marginalised cohorts to mitigate widening disadvantage?
- How does the proposal acknowledge that disability diagnosis requires access to the medical system and that this access isn't equitable?

Principle 6: Accessibility

One young person participating in the consultation described the inaccessibility they experience in day-to-day life due to their communication needs not being met.

> *"I've had a lot of experience being deaf and not being able to access anything in the community and being denied even basic shopping services because I communicate either with an interpreter or a phone, with a text to speech app. I think it's really important to highlight different communication ways, especially when we have such high tech nowadays. It's really important that for one, it's non-discriminative against, but also can't be denied. That's really important".*

Another, was similarly concerned about the difficulties of engaging in the community due to their communication requirements.

> *"A lot of disabled people have different ways of communicating, and that makes it difficult to engage with the public often, and there's discrimination stuff. I personally am an AAC[25] user. I'm semi speaking and autistic".*

One young person pointed out how many of the accommodations that create accessibility are quite straightforward.

> *"If it is just an office job or whatnot, sometimes we just need a bigger computer monitor, or something like that. I think there needs to be more understanding that sometimes assistance isn't a massive thing, and it can just easily be integrated. It doesn't need to always be such a big deal. It can just be small things".*

Another young person highlighted the ways in which ill-considered accommodations can make services and experiences inaccessible.

> *"When I first started [university] I met with disability services to come up with an action plan, to try and get me through uni. We gave them a bunch of documentation to try and help inform that action plan. And the one I got was just completely terrible.*

---

[25] Augmentative and Alternative Communication – methods, systems, tools and strategies to support communication

It just painted me in a really, really negative light. It pretty much – it would have had me pretty much stripped of all my dignity, in a sense. So yeah, we really gave disability services 'what for' that. And my second plan – and I still haven't read through it, because I just gave up and decided to go it on my own. Somehow I managed to graduate without an action plan".

These examples highlight the additional labour, intellectual, physical and emotional, that people with disability often do in order to have their needs met in an environment without principles of universal design and access embedded in.

Resources developed to support this principle should account for the breadth of approaches and accommodations that fall within the umbrella of accessibility and provide users with methods for discovering these. They should also consider that people with disability are commonly in a position where they lack access to everyday services and experiences which require them to expend valuable energy attempting to create accessibility for themselves.

Change existing questions to:
- In what ways have aspects such as the information, technology, services and location, been designed to ensure people with disability are able to access this proposal?
- Which principles of universal design have been applied in the proposal and how?

Additional prompts should include:
- Has the proposal included a consultation with people with disability and their families and carers to determine a range of appropriate supports and accommodations that will be made available to achieve maximum accessibility and participation?
- How does the proposal ensure participation for people with a wide range of communication needs and preferences and the fact that this might fluctuate? For instance, non-speaking AAC users, Auslan speakers, and Braille users.
- How does the proposal ensure that the accommodations and access it provides do not inadvertently cause negative impacts?
- How is accessibility extended to people with disabilities that have not disclosed their disability?

Principle 7: Equality of people

Participants agreed that this principle was very similar to principle 5 which focuses on equality of opportunity. Further work needs to be done to define and provide examples of cultural safety and appropriateness in relation to potential proposals. Equally, clarity around the terms full-development, advancement, and empowerment is needed. CYDA recommends this be defined by the users of the proposal, in this case people with disability, and has reworded this prompt accordingly.

CYDA's submission to DSS on Guides for Australia's Disability Strategy

Change existing questions to:
- How can this proposal embrace and celebrate diversity, including in relation to gender, age, sexuality, race, or cultural background, in order 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?

Additional prompts should include:
- What ensures definitions related to equality, such as cultural safety and appropriateness, are operationalised in proposals?

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

CYDA's response to this principle considers the context of young people's feedback on the previous seven principles as well as experiences related more directly to their identity as children and young people with disability. The extent of data presented in this principle also reflects our role as advocates for children and young people with disability.

A young person who was unable to participate in our recent consultations, provided written feedback on this principle, highlighting the specific resources and support required to address the transition from childhood to adulthood.

> *"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".*

CYDA commonly hears feedback from young people that they feel underestimated and patronised in their interactions with adults, especially in an institutional context. A participant from our consultation on this topic exemplified this with the following statement.

> *"I think something that a lot of young people do experience is patronising, I guess language and behaviour, especially when they're younger. Whilst I do think it's important that children with disability should be treated with the same respect as they are as they grow older, it's also seeing that they're not disrespected as well, in the same way as when they're younger. And making sure that if they are in physical spaces that there are appropriate child safety things so we're not dealing with any SASH[26] issues".*

The following three participants also reflected on similar experiences directly related to their age and the perception of their experience and maturity that often occurs alongside this.

> *"I really wish when I was younger that adults, especially in the community, had taken time to listen because I think it would've saved a lot of stress growing up with*

---

[26] Sexual assault and sexual harassment

CYDA's submission to DSS on Guides for Australia's Disability Strategy

disability and being allowed to actually speak about what I was going through rather than just being dismissed as a kid making stuff up".

"I've realised that as a disabled person and especially a disabled teenager and someone who's autistic, I get treated like I'm a little child".

"It can be very traumatic to have your life literally laid out in excruciating detail from when you're a child to be told you're just anxious, you're just traumatised and no wonder we're traumatised when we're not listened to."

The problematic imbalance of power between children and adults has already been discussed in relation to CYDA's recommendation for a feedback and complaint mechanism to be provided as part of these principles. However, it is critical that any proposal involving and impacting children attend to the increased risk of mistreatment that children with disability experience due to additional contact with adult led services.

It is CYDA's position that any proposal that impacts children and young people with disability should be developed in consultation with them and in keeping with the National Principles for Child Safe Organisations[27] which were informed by the findings from the Royal Commission into Institutional Responses to Child Sexual Abuse[28].

In particular, the second child safe principle, "Children and young people are informed about their rights, participate in decisions affecting them and are taken seriously", arose directly from findings by this Royal Commission that strengthening the ability of children to participate in decisions that affect them, is a key component of ensuring their safety.

Our consultations demonstrated that young people have the desire to advocate for themselves where possible and be given choice and autonomy, as the following two participants explained.

"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".

"I think it would be cool if there was a focus on independence and autonomy because I think that […] children should be given respect. I think that they should also be given a little bit more choice than they currently are. I know there's a wide range of disabilities, but I think that they should be able to choose the direction they want to move in."

CYDA recommends additional and specific resources be co-designed with this cohort and representative organisations to support the implementation of this principle. For instance, example codes of conduct, case studies to enable youth representative programs, guidelines for developing mentoring programs, examples of feedback and complaint processes design with children and young people in mind.

---

[27] Australian Human Rights Commission. (2018) *National Principles for Child Safe Organisations*. Available at: https://childsafe.humanrights.gov.au/national-principles
[28] Royal Commission into Institutional Responses to Child Sexual Abuse. (2017). *Final Report*. Available at: https://www.childabuseroyalcommission.gov.au/final-report

CYDA's submission to DSS on Guides for Australia's Disability Strategy

Change existing questions to:
- How are children with disability being supported and included to ensure that they are able to participate and be engaged with on an equal basis to their peers without disability?
- How have the best interests of the child been determined and framed as a primary consideration?
- What supports and accommodations are being offered to ensure children and young people with disability are able to participate in decisions on an equal basis to their peers without disability?

Additional prompts should include:
- In what ways has the proposal been co-designed with children and young people with disability and their families and carers to design in a range of appropriate supports, accommodations and safety mechanisms to ensure accessibility and participation?
- How has this proposal integrated the National Principles for Child Safe Organisations?
- What provisions have been made for children and young people with disability to participate without relying on their primary carer?

CYDA's submission to DSS on Guides for Australia's Disability Strategy

3. A Guide to Involve People with Disability in Evaluation: CYDA's response

3.1 Proposed best practice principles for involving people with disability in evaluation

The following impression, shared by a young person participating in CYDA's consultation on evaluation, underpins CYDA's recommendations for approaching a Guide to Evaluation.

> *"The framing of the principles was very much with the disabled people as bystanders as opposed to being key stakeholders in the evaluation process".*

Co-design as an overarching aim of evaluation

Based on CYDA's ongoing consultation with children and young people with disability, including consultations specific to this submission, we recommend reframing the approach to developing the evaluation guide and foregrounding the expertise and lived experience of people with disability. The title of the guide and the principles should reflect this framing. For instance, **'Best practice principles for partnering with people with disability in evaluation'**.

CYDA promotes genuine co-design as best practice for inclusion and therefore we recommend co-design as the overarching aim that the principles are designed to achieve. Co-design was a recommendation in a research report from the Disability Royal Commission, which specifically stated that such an approach validates "the collective voices and lived experience expertise of people with disability in the way the interventions are designed and conducted"[29]. In the context of a guide to evaluation this would mean that the first step for organisations would be to set up a co-design working group to ensure the remainder of the evaluation process was carried out in partnership with people with disability. Additionally, it is imperative that any proposal impacting young people with disability have representatives from this cohort in the working group. Ideally, people with disability would already be part of a reference group, or similar, for larger or more substantial ongoing projects.

The co-design approach was reflected in our consultation with young people regarding evaluation. For instance, one young person shared a comment via written feedback that encapsulated the experience of 'othering' that people can feel when consulted in inauthentic ways.

> *"It's important that you place [people with disability] in a position to run and be part of making/writing up the evaluation report and not just placing us to be the subjects of it".*

Another young person participating in the consultations shared their thoughts on the process of co-design.

> *"I guess what I was thinking was allowing disabled people to be consulted at multiple stages throughout the design process of the evaluation, initially before anything is designed, looking at what the goal is, what the information they're trying to get out of the evaluation is and helping to suggest ideas of going about this, questions to ask,*

---

[29] Fisher, K. Et. Al. (2022). *Research Report: Changing community attitudes to improve inclusion of people with disability*. Available at: https://disability.royalcommission.gov.au/publications/changing-community-attitudes-improve-inclusion-people-disability

CYDA's submission to DSS on Guides for Australia's Disability Strategy

et cetera and then being able to come back and see the draft of what's being created, give feedback on that.

And then even if it's just sending through the final draft and giving an all-clear and just being able to provide feedback throughout it, provide your own opinions and it's even better if they are able to have disabled people on board within the team themselves that are creating the evaluation but that's of course up to the organisation, would be my thoughts".

As this young person suggests, understanding what the goal is from the beginning of the evaluation process is an important part of co-design. CYDA recommends children and young people with disability be part of defining what success looks like in the context of the proposal being evaluated. Views about success may differ between cohorts so it is important to recognise this and seek to understand those perspectives.

With co-design as an aim rather than a principle, CYDA recommends the first principle be 'establishing co-researcher and leadership roles for people with disability'. Representatives from the disability community, including young people with disability, should already be part of evaluation teams at the beginning of the design process.

We recommend providing detailed examples of key terms used throughout the principles and phases of evaluation listed in the consultation document. For instance, what does 'respectful' and 'safe' mean when working with people with disability.

CYDA recommends the Evaluation Guide include supplementary information on ways for organisations to invest in programs that support various cohorts within the disability community, such as young people, to design evaluation programs of research and collect data from their own peer group. For instance, the project team for 'Adulthood for Gen Zs with Down Syndrome' at the University of Queensland includes young people with Down syndrome who collect data for the project. The lead researcher on the project, who doesn't have lived experience of disability herself, notes that she values the expertise of those on the team with lived experience [30].

3.2 Proposal for actively involving people with disability across the evaluation cycle

The feedback we received from children and young people on evaluation does not readily fit into the design phases listed in the consultation document, therefore the following sections provide our overall feedback and recommendations on all aspects of evaluation from the perspective of children and young people with disability.

Create opportunities for contributions that are meaningful and impactful

CYDA's work with children and young people with disability and their families has previously found that people with lived experience of disability are often cynical of being consulted in disingenuous and non-impactful ways.

"If you're going to consult, you need to genuinely want to consult. Listen and be ready to make changes and take action on what people with disability are actually saying to you. Don't just do it to tick a box." Participant in Good Practice Guidelines for Engagement of People with Disability – November 2022.

---

[30] See ABC News article. Available at: https://www.abc.net.au/news/2022-03-31/uq-hires-four-new-employees-with-down-syndrome/100950152

CYDA's submission to DSS on Guides for Australia's Disability Strategy

The aspiration to contribute in meaningful ways was shared by participants from CYDA's recent consultations on the topic of evaluation. The following participant notes their desire for involvement and uses the term "us based" to describe disability issues.

> *"I think just really getting us involved in anything really is just really the main way to go in order to have a proper – I want to say outcome but a proper actual voice or an understanding of us based issues. Because a lot of the time, even for us based issues they won't bring in disabled people".*

Another participant mentioned the desire for genuine and continuous involvement.

> *"Don't bring in people on not even a casual basis to give their thoughts and opinions on things like this. Actually establish some sort of position or whatever that gives us the ability to, if you want our voices and our opinions fine, but we'd have the right to be – on the continuous basis, yeah fine. But we need everything else that comes with the continuous basis. So proper payments, super, all that kind of stuff".*

CYDA works with groups of people who participate in consultations on a regular basis, and they commonly share their desire to understand the impact of their contribution.

> *"It would be good to just have sort of like feedback to say that, yes, your contributions were helpful, and this is what we're going to do about it and how we're going to go around doing it".* Participant in Good Practice Guidelines for Engagement of People with Disability – November 2022.

And young people shared that they want to know they have had an impact on decisions.

> *"Involve people with a disability in decision making".*

Include young people to gather diverse perspectives through a variety of channels

Young people we consulted were concerned that any evaluation process should ensure that a diverse range of perspectives are gathered from a diverse range of people. Children and young people have preferences for technology and media platforms that adults might not be aware of, therefore it is imperative that they be included in decision making across the evaluation process in order to successfully gather diverse and difficult to reach perspectives.

For instance, one young person shared:

> *"I would say holding consultations similar to this and making sure that in each stage that you are having, say, consultations or feedback sessions or anything like that, you are making it accessible to all kinds of disabled people, [from] a range of different disabilities, LGBT, culturally and linguistically diverse backgrounds, different socioeconomic statuses, making sure that there is a wide range so you actually are getting […] diverse answers for the evaluation".*

Others, such as this young person who wrote in the chat function of our consultation, raised the idea of providing a diverse range of options for contributing.

> *"Having multiple ways to contribute thoughts, i.e., surveys and Zoom consultations".*

Another agreed, highlighting the possibility of reaching a wider variety of people by using online platforms.

> *"I'm just thinking that maybe the evaluation could be as inclusive as possible, try to have as much disability types as possible if that makes sense. […] Have Zoom*

CYDA's submission to DSS on Guides for Australia's Disability Strategy

meetings are a good start because we can get as many people in from various different places."

Create accessibility to maximise opportunities to contribute

Accessibility was extremely important to young people when thinking about the design of all phases of the evaluation process to enable participation. For instance, one young person mentioned the range of communication differences that could be accommodated.

> *"I think it's also important to include making it accessible for people with different communication needs. I know when I worked on the Youth Summit this year, we had people with deafness, with vision issues, at one point we had someone that I believed used an AAC device [which] obviously made it a little bit complex […] but also made it really, really good because everyone was included and ways of communication were kept in mind then with the further planning. So, I think it's important that we include different needs of communication by making it accessible for people with communication needs because it's easy for people to say they want disabled people but a lot of time what I find when I get involved in health-related things is there won't be captions available or it's not vision friendly and they don't have the space or the time willing to make it accessible for everyone, so I think that's really important".*

Another participant shared the following as a simple way to consider the needs of people when seeking their feedback and opinion.

> *"Doing little things like, […] if you need to talk about your opinions on a big amount of text, like what we are doing [here], for example, copy and pasting it into the chat so people like me who have processing issues can remember what the key points are so I can remember exactly what we're doing and following along".*

Similarly, a young person added the following notes, through written feedback, on inclusive language and access for young people participating in evaluation:

> *"I think being mindful of the language used, especially for youth, evaluations can seem very formal, we want to avoid alienating any age groups".*

> *"Ask what people's access needs are well in advance and ensure that we can meet them all. E.g., booking interpreters early is key".*

One young person in our consultations, sharing via the chat function, was also concerned about the expertise and approach of facilitators within the consultation process of evaluations.

> *"It's crucial that there are trauma informed people with some level of lived experience acting as facilitators for focus groups and consultations, 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."*

CYDA's submission to DSS on Guides for Australia's Disability Strategy

Provide fair recognition for the expertise of those who contribute

Participants noted the importance of being acknowledged and compensated for their time and expertise. One participant used the chat function to say, *"I think it's important for disabled people to be financially compensated for their time"* and another agreed, saying, *"I've done quite a few of these type of meetings with different places and quite often, the money I have received if any has been quite small".*

Ensuring the evaluation is resourced to financially recognise the contributions of those involved must be considered at the planning stage of the process. To that end, CYDA recommends amending Principle A to read "Informed, transparent and resourced" so that resourcing of evaluations is considered at the outset, not as an afterthought.

CYDA's submission to DSS on Guides for Australia's Disability Strategy