



"A New Act to Replace the Disability Services Act (1986)"

Submission in response to the Department of Social Services consultation paper

Centre for Disability Research and Policy

12 February 2023

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We wish to thank the Department of Social Services for the opportunity to contribute to the proposal for "A New Act to Replace the Disability Services Act (1986)".

The comments in the below submission have been informed through the survey and workshop consultations organised by the Centre for Disability Research and Policy (CDRP), with stakeholders including people with lived experience of disability.

We wish to thank the members of our community who contributed their insights and lived experience to this submission:

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Comments on Proposed updates to the Act

Objects of the Act

QUESTION 1: Do you agree with the proposed objects for the new Act? What other objects should be included in the new Act?

Do you agree with the proposed objects for the new Act?

The first object for the new Act identifies it as one of a number of laws that will demonstrate Australia’s obligation to act as a signatory to the Convention on the Rights of Persons with Disabilities (CRPD, 2006) [2008]. It is appropriate to state how the new Act will contribute to our national effort to meet international treaty obligations.

But it is not appropriate to restrict the remaining objects to a narrow selection of CRDP terms and assumptions to limit the scope and likely impact of the Act.

We commend that the CRPD is the starting point and everything flows from there however, this is the first time to update the act, and we should be more ambitious. The **language should be more progressive**, and we need to start from a place of asserting a person with disabilities’ rights to citizenship.

Specifically, the proposed objects (b) – (e) appear to adopt an **adaptive** rather than **transformative** approach to the naming and framing services. This reflects a **deficit/barriers** approach (evident in the CRPD Clause E Preamble) rather than an **inclusion/participation** approach evident in current Australian disability advocacy, lived experience and best practice service. The words ‘impairment’, ‘barrier’, ‘support’ and the exclusive naming of ‘social and economic’ as target fields of action are indicators of a ‘business as usual’ based on a narrow application of the CRPD.

It is recommended proposed objects (b) – (e) are formulated using **value-free concepts** stated in the first paragraph of Article 1 of the CRDP “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”. Note the word ‘support’ does not appear here. Also note the culturally specific notion of ‘independence’ does not appear here.

Instead, the new Act objects should use words from Article 3 of the CRPD General Principles (also known as Guiding Principles). These do not restrict understandings of the scope, scale or intention of services to a narrow use of impairments/ barriers/ or specific fields of action such as social or economic.

There are 8 General/ Guiding principles that have enduring relevance to contemporary society. These principles provide a platform for transformative action and inclusive understanding to achieve the purpose of the CRDP.



"The principles of the present Convention shall be:

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

Comments related to a)

Consider identifying CRPD articles to which this Act has particular relevance, such as:

Article 8 – Awareness-raising

Article 9 – Accessibility

Article 19 – Living independently and being included in the community

Article 26 – Habilitation and rehabilitation

The objects of the Act should also **include a statement about the rights of people with disability**, closely aligned with wording in the CRPD, e.g.,

- Preamble (y) 'to promote and protect the rights and dignity of persons with disabilities ... redressing the profound social disadvantage of persons with disabilities and promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities,'
- 'Article 1 – Purpose. ... to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.'
- Article 3 - General principles
- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- Full and effective participation and inclusion in society

Comments related to b)

The wording of proposed object (b) should be expanded and strengthened to convey that the Act aims to **support the full participation of people with disability in all aspects of life**.

Again, wording of this object should draw upon the text of the CRPD. For example,

- Preamble (y) '... promote their participation in the civil, political, economic, social and cultural spheres with equal opportunities,'
- 'Article 3 - General principles –
... freedom to make one's own choices, and independence of persons;
- c. Full and effective participation and inclusion in society'

It should also include wording from the Foreword of Australia's Disability Strategy 2021-2031, For example, people with disability can participate as equal members with equal opportunities to fulfil their potential.'



The word ‘services’ not ‘support’ should be used. This is because ‘support’ suggests an individualised approach to action, whereas sector-wide or systemic services may be more efficient and effective.

We advocate for **including the person’s “family, carers and kin” in all aspects of the Act** including at b)

Comments related to c)

The wording of proposed object (c) is ambiguous and needs to be clarified. The clauses that follow ‘including by’ are not examples of how the Act will achieve this object, but rather the desired outcomes for people with disability. This object is worded in terms of ‘providing’ services, rather than funding services. It is important to ensure that the Act provides authority for the Commonwealth to both fund and directly provide services.

We also advocate for **stronger language that includes the role of a person with disabilities’ informal supports, including their family, carers and kin**, as well as participation across a broader range of meaningful opportunities.

- c) provide supports and services which empower people with disability to maintain and increase their social and economic participation, including by:
- i. participating on an equal basis in ~~their~~ communities of **their choice alongside their family, carers and kin**
 - ii. increasing independence and seeking meaningful opportunities for **social connectedness**, employment, education, and **personal** development
 - iii. understanding and enjoying their inherent human rights and fundamental freedoms

We recommend that **this object address Article 3 CRDP guiding principle C of ‘full and effective participation in society’ and guiding principle A of ‘respect/ autonomy/ freedom in choice-making’**. The object should state that services will embody these principles without restriction to particular fields of action (social, economic, education, employment, development) in ways that assume particular models of engagement (empowerment is only one approach).

Object c) should also reflect the guiding principle B of non-discrimination and define that **‘services’ include activities that promote, protect, and ensure non-discrimination**. This may include advocacy, provider advisory agencies, safeguarding activities and so on.

Comments related to d)

We advocate for **stronger language which places the person at the centre of all decision impacting on their life**. Suggestion – “place the person with disability at the centre of decision-making in how they are planned, developed, implemented and reviewed”.

Proposed object d(ii) should be split into two or three parts, to address effectiveness, quality and innovation separately. We call into question the notion of “effective” supports. This needs to go beyond just a word, to actually having some meaning, that there is actual data to show that if you do A, you will do better than if you do B. There should be a strong commitment to disseminating what works. If people with disability don’t have any data on the performance of the services that they are choosing between, or indeed any data on what actually works, they are unable to make an informed choice which renders it meaningless. When determining a service as effective, the DSA needs to flesh out what data is necessary to inform this.



We advocate for all forms of knowledge, including quantitative and qualitative data and most importantly, data derived from the lived experience of people with disability. Regarding the use of the word innovative, it may be appropriate to use the wording of object (e) in the current Act: ‘to encourage innovation in the provision of services for persons with disabilities’.

Therefore, to support the notion of effectiveness there should be a third point under d) which mandates that there is **independent and accessible information and data that helps people with disability make choices about services that they have, and they need.**

Finally, we would like to ensure services and supports recognise the needs of particular groups, including being culturally safe for Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse people. The [NSW Disability Inclusion Act 2014](#) sets out principles recognising the needs of particular groups and should be used to align with the Disability Services Act.

Comments related to e)

We strongly advocate for the removal of the term acceptance of people with disability and towards recognition that people with disability are active contributors to society. It is time to change the language and the discourse around disability as a deficit and move towards **championing diversity**. The wording of proposed object (e) should be strengthened to align with CRPD Article 8 - Awareness-raising:

- 1 a. To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;*
- b. To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;*
- c. To promote awareness of the capabilities and contributions of persons with disabilities.*

The current object misses the important elements of respect and difference – including these concepts aligns the new Act objects with national inclusion initiatives across a range of issues.

What other objects should be included in the new Act?

The consultation document suggests some additional objectives of the new Act that are not captured by the proposed objects:

- **Provides authority to fund services for all Australians with disability**, including those who are not eligible for the NDIS, and expands the types of financial mechanisms that can be used
- **Sets out key principles for service delivery** and ensures authority to continue current service delivery
- **Includes updated quality and safeguard standards arrangements and requirements**, including compliance, reporting, review and complaints mechanisms that align with the best practice for disability services.



In addition, an object about **ensuring regular, standardised data capture and reporting** should be added, covering data on (i) the nature and quantity of services and supports provided, (ii) characteristics of individuals to whom services and supports are provided, (iii) the quality of services and supports provided, and (iv) associated outcomes for individuals to whom services and supports are provided. Such data are essential for transparency and accountability, to identify unmet needs, and to inform ongoing improvements to policy and practice in order to improve outcomes for people with disability.

The current Act includes object (d): 'to ensure that the outcomes achieved by persons with disabilities by the provision of services for them are taken into account in the granting of financial assistance for the provision of such services'. It would be valuable to include an object along similar lines in the new Act, strengthened to convey that ongoing funding of services will be contingent upon those services meeting criteria concerning quality and effectiveness.



Who will the new Act support?

QUESTION 2: Do you agree with the proposed approach to the target group? How do you think the target group should be defined?

We commend the move away from the medical model in defining disability and towards the social model of disability, recognising that disability results from the impact of environmental and societal barriers that hinder full and effective participation in society on an equal basis with others.

However, as a group we are concerned about the use of barriers as a way to define a person’s disability support and service needs, and that some people would be excluded if they did not fit under a pre-defined set of barriers. Instead of talking about barriers, we need to shift this language to what people need. Not everyone will identify with the same type of barriers, even if they have the same type of disability. Therefore, **the focus should be on support needs, not barriers.**

Many people, including neurodivergent people, may not identify with having a disability, yet still, need support and accommodations. The target group within **the Act should ensure that the application of the Act encompasses all services/supports for people with disability**, and that its application is not inadvertently narrowed by use of wording that can be interpreted to exclude some people with disability. By focusing on the social model of disability, we take into account individual choice, how people want to identify themselves, and do not exclude people on that basis.

We do not agree that the NDIS disability requirements definition has its place in the Disability Services Act and that target group should be defined to align closely with the broad conceptualisation of disability in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) definition:

‘include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’.

The new Disability Services Act should aim **to define the target group to include the full diversity of people with disability**. As it is not the role of this Act to define target groups eligible for specific programs or services (as, for instance, the definition in the NDIS Act is), there is no reason to define the target group more narrowly than the conceptualisation of disability in the CRPD.

With regards to the use of ‘long term’ in defining disability and eligibility for supports and services, it is unclear what constitutes long-term and this can have major impacts on access and eligibility for disability supports. In Australia, the [Australia Bureau of Statistics’ Survey of Disability Ageing and Carers](#) is used to provide prevalence estimates of disability and profiles of people who experience difficulties functioning in everyday life. The Survey’s operational definition of disability is ‘any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months’.



We also advocate for aligning with amendments to the [NSW Disability Inclusion Amendment Act](#), updated in 2022, which includes provisions for young children and persons with varying levels of support needs. This will ensure children and people who may have short-term support needs will not be excluded based on the use of the word long term or permanent.

(3) A person in the relevant group includes a child under 6 years of age who has developmental delay within the meaning of the National Disability Insurance Scheme Act 2013 of the Commonwealth.

(4) To avoid doubt, a person with a permanent disability is a person in the relevant group even if the severity of the person’s impairment because of the disability may diminish over time or the person’s condition may improve.

Explicit recognition of intersectionality would be of value in defining the target group, as this would draw attention to the issue of some people with disability experiencing greater disadvantage due to being members of more than one disadvantaged group. First Nations people, women, LGBTIQ+ people, and people from culturally and linguistically diverse backgrounds should be specifically mentioned. Wording from the CRPD Preamble could be adapted for this purpose:

‘(p) Concerned about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status’.

QUESTION 3: Do you agree with our suggested principles for avoiding duplication and requiring coordination? What other principles do you think should apply?

Duplication and lack of coordination represent longstanding disability policy issues. Decades of policy efforts to integrate disability services for people with complex needs have failed to address fundamental challenges.¹ One of the key challenges is a **separation of Commonwealth and state responsibilities, together with institutional boundaries, that continue to constrain collaboration among health and disability service sectors.**² Greater policy efforts are therefore needed to avoid the duplication of disability services and to operate in a strategic manner so as to maximise the use of sparse resources (particularly in rural and remote areas).³ It is therefore important that the New Act is based on practical principles which can help to progress these outcomes.

Silos and administrative red tape that negatively impact on disability services persist and need to be removed. For example, there are disability employment service providers who get caught up with arduous government reporting procedures and paperwork at the expense of

¹ Glasby, J. (2017). ‘The holy grail of health and social care integration’, *British Medical Journal*, 356. doi: <https://doi.org/10.1136/bmj.j801>

² Hummell, E., Venning, A., Foster, M., Fisher, K. R., & Kuipers, P. (2022). A rapid review of barriers and enablers of organisational collaboration: Identifying challenges in disability reform in Australia. *Australian Journal of Social Issues*, 57(2), 441-457.

³ Bohanna, I., Harriss, L., McDonald, M., Cullen, J., Strivens, E., Bird, K., ... & Barker, R. (2022). A systematic review of disability, rehabilitation and lifestyle services in rural and remote Australia through the lens of the people-centred health care. *Disability and rehabilitation*, 44(20), 6107-6118.



their clients with disability.⁴ With vertical funding silos also hindering collaborative efforts, the vital role played by governments in terms of revising funding structures to enhance collaboration across sectors is well established.⁵ Hence, the literature supports **joint funding across sectors as an effective way to encourage collaboration** and to prevent the duplication of disability services.⁶

There is a need to acknowledge potential political resistance by stakeholders to ‘protect their patches’ in any policy efforts to promote coordination or to remove duplication. The new Act is therefore challenged to address the organisational power imbalances that can severely impede collaboration.⁷ Furthermore, as legislation has traditionally struggled to clarify how it is to advance collaboration and coordination⁸, care is needed to ensure that the new Act can provide this clarification.

One of the key principles that is fundamental to coordination of disability services is the notion that **disability is everyone’s business** and that all services need to be responsive and supportive to people with disability. Attitudes framing disability as “not my area, not a focus of my service/agency/business” contributes to the development of poor coordination and fragmentation. This new Act needs to have a far-reaching vision to engage all agencies, services and businesses to see the disability community as part of their potential service users.

The proposed principles lack the specificity required to give practical effect to ensure that the ‘gaps, cracks, and overlaps’ across the broader health and human services systems at State and Federal levels do not frustrate the objects of the Act.

People with disability and their supporters, including the specialist disability services they choose to support them in pursuit of social and economic goals, repeatedly cite evidence of cost and blame shifting, even when other principles such as those developed for NDIS Participants (the Applied Principles and Tables of Supports) are already in place^{9,10}. Building on principles such as those already in place for the NDIS, Australian Governments, through COAG and the Disability Reform Council, should consider **developing principles that operationalise the objects of the new Act across all State and Territories** (i.e. beyond just the NDIS population which are a minority of Australians living with a disability and that

⁴ Mellifont, D. (2017). DESperately Seeking Service: A narrative review informing a disability employment services reform framework for Australians with mental illness. *Work*, 58(4), 463-472.

⁵ Green, A., Abbott, P., Luckett, T., Davidson, P. M., Delaney, J., Delaney, P., ... & DiGiacomo, M. (2020). Collaborating across sectors to provide early intervention for Aboriginal and Torres Strait Islander children with disability and their families: a qualitative study of provider perspectives. *Journal of Interprofessional Care*, 34(3), 388-399.

⁶ McQueen, D. V., Wismar, M., Lin, V., Jones, C. M., & Davies, M. (2012). *Intersectoral governance for health in all policies. Structures, actions and experiences*. Geneva, Switzerland: World Health Organization.

⁷ Pearson, C. and Watson, N. (2018). Implementing health and social care integration in Scotland: Renegotiating new partnerships in changing cultures of care, *Health & Social Care in the Community*, 26(3), e396-e403.

⁸ Hummell, E., Venning, A., Foster, M., Fisher, K. R., & Kuipers, P. (2022). A rapid review of barriers and enablers of organisational collaboration: Identifying challenges in disability reform in Australia. *Australian Journal of Social Issues*, 57(2), 441-457

⁹ Warr, D., Dickinson, H., Olney, S., & et al. (2017). Choice, control and the NDIS. Retrieved from <https://apo.org.au/node/93036>

¹⁰ Yates, S., Carey, G., Malbon, E., & Hargrave, J. (2021). 'Faceless monster, secret society': Women's experiences navigating the administrative burden of Australia's National Disability Insurance Scheme. *Health Soc Care Community*, n/a(n/a). doi:10.1111/hsc.13669



can rely on the Applied Principles through relevant complaints and appeals procedures such as the AAT). More detailed Principles would give greater practical effect to the timely, predictable resolution to cases where a person is eligible for services and supports under more than one piece of legislation. The **Acts principles should support a “no wrong door” approach, which is more flexible** about the time and place a person with disability is seeking services and supports. Sometimes, the strict interpretation of principles like the ones proposed can frustrate the aims of the Act itself. For example, until recently it was not possible to be a School Leaver Employment Service (SLES) client aged 18-22 years and also be a Disability Employment Services (DES) client. This means that SLES graduates had to wait till SLES ended, on their 23rd birthday, before receiving job search assistance from a DES provider, usually resulting in long delays and loss of skills and motivation. The proposed principles, intended to avoid “double dipping” across service and supports, could ultimately frustrate employment outcomes, where Australia performs relatively poorly within the OECD.

This highlights one of the issues that requires clarification by Australian Governments in relation to the new Act - the current status of **the principles to Determine the Responsibilities of the NDIS vs Other Service Systems** (Applied Principles and Tables of Supports)¹¹. These Principles were introduced in 2015 during the launch of the NDIS and represent a more elaborate and detailed set of principles than those proposed for the new Disability Services Act to guide co-ordination at the interface between NDIS funded services and supports in relation to other (mostly Federally funded but State run) service systems.

The introduction of the NDIS, in some cases, has made the gaps between policy aims and lived experience worse. People with disability that need services and supports now have the added frustration that service providers working with individualised funding arrangements under the NDIS are more reticent to support them in service environments where they are not funded to do so. Whilst many service providers continue to “follow the person”, consistent with mission-oriented ambitions, there is growing evidence that this is detrimental to the disability service system itself¹². In the absence of coherent strategy and appropriate funding for individual advocacy, support co-ordination, and service navigator roles such as Local Area Co-ordinators, **evidence is emerging that personalisation schemes are potentially entrenching inequality for some**¹³.

The reasonable expectation that, under the previous National Disability Strategy and the introduction of significant reforms such as the NDIS, mainstream services would develop the capacity and capability to offer person-centred responses has not been realised. If the new Act does not address this ‘rhetoric – reality gap’ then the opportunity to set more progressive, ambitious policy for Australians living with disability will be lost for another generation.

The proposed wording ‘should not duplicate or substitute services and supports provided under other legislation’ lacks clarity and could be open to interpretation and potentially be used by the Commonwealth government to argue that it should not provide supports of a

¹¹ Principles to Determine the Responsibilities of the NDIS vs Other Service Systems (Applied Principles and Tables of Supports). Accessed at [How do we work out who should fund or provide your supports? | NDIS](#) 8.02.2023

¹² Carey, G., Dickinson, H., Malbon, E., Weier, M., & Duff, G. (2020). Burdensome Administration and Its Risks: Competing Logics in Policy Implementation. *Administration & Society*, 52(9), 1362-1381. doi:10.1177/0095399720908666

¹³ Carey, G., Malbon, E., & Blackwell, J. (2021). Administering inequality? The National Disability Insurance Scheme and administrative burdens on individuals. *Australian Journal of Public Administration*, 80(4), 854-872.

doi:<https://doi.org/10.1111/1467-8500.12508>



particular type if they are already funded by another Australian government. **The principle should be that all people with disability can access the services and supports they need**, and that it should not be up to the individual to navigate the complexities of programs provided by different levels of government. Rather, the onus should be on **all Australian governments to work together to ensure that programs are available to meet the needs of all individuals**, to determine the division of responsibility between programs and levels of government, and to put arrangements in place so that individuals can access the services and supports they need as simply as possible in a timely manner.

The Act should convey a clearer intent, reflecting evidence from international jurisdictions, about the benefits of ‘whole systems’ working for people with disability, their families and carers. Hence “all governments must continue to consider and uphold the rights of people with disability, consistent with the Strategy...**and are jointly responsible for outcomes.**”

A related key issue that is raised in any discussion about delineation of responsibilities for services and supports, is the extent to which the broader health and human services system across different levels of government should rely on a **common assessment framework** and tools, and the **portability of citizen beneficiary information pertinent to supporting people across multiple service systems**. Australian disability policy and practice has suffered for many years from the absence of a ‘disability identifier’ applied across the full range of government and non-government service environments that people with disability engage with. This speaks directly to the need, not just for coordination of services already provided, but access to services and supports based on common assessment framework and tools. For example, there are WHO- ICF strength based and holistic assessment tools already in use by the Federal Department of Health (i-CAN) which could have broader applications. Subject to relevant privacy and confidentiality restrictions, these could improve the efficiency of the government in avoiding unnecessary duplication of assessment for the purposes of accessing services and supports provided under the new Act relative to other legislation. Similarly, assessments undertaken for the purpose of accessing the NDIS might support the **development of a ‘whole of government’ person-centred assessment model** to underpin fairer and more consistent access, planning and resourcing across services. A recent technical paper of the International Classification of Functioning, Disability and Health Australia Interest Group (ICF-AIG) canvasses these issues in more depth¹⁴.

The new Act, in asserting a principle of “no wrong door” could give momentum and practical effect to some of these ideas and achieve a generational shift in the experience of people with disability that rely on multiple service systems.

¹⁴ See The ICF and its potential uses in the NDIS, ICF Australia Interest Group, April 2022. Accessed at [Health classifications and terminologies - Faculty of Medicine and Health \(sydney.edu.au\)](https://www.sydney.edu.au/medicine/health-classifications-and-terminologies).



Definition of disability

QUESTION 4: Do you think the new Act should include a definition for disability? Do you have any additional comments?

There is a place to retain a definition of disability within the Act alongside the identification of support needs. There is a need to recognise the complexity involved in defining disability. Defining disability is historically shown to be a challenging task.¹⁵ However, we note that a definition of disability is needed in the new Act to allow for data collection and policy/program evaluation purposes. Whether a person is identified as having a disability by government, the state and their peers holds significant consequences in relation to the opportunities that they receive and their life prospects more broadly.¹⁶

Given this importance, any **definition of disability as applied in the new Act must be inclusive so that people are not left out**. Specifically, the new Act needs to include individuals who choose to identify in different ways.¹⁷

Policymakers need to ensure that the use of a definition of disability which is steeped in medical model ideological influence, as evidenced in the *Disability Services Act 1986*, is not replicated in the new Act. In particular, the DSA 1986 negatively constructed people with disability as incapable as a consequence of their disability.¹⁸ This approach, popularly espoused among the medical community, has been strongly criticised for its focus on impairment.¹⁹ The pathology paradigm and its emphasis on ‘disorder’ has resulted in neurodivergent people being misrepresented, stigmatised, abused and traumatised.²⁰ **Medical model-oriented definitions of disability can also act as barriers to accessing services** for people who do not identify as disordered and who yet still need support.

Conversely, under a social model of disability, the disability rights community sees disability stemming from the social prejudice that excludes people with disability.²¹ It is therefore important that any definition of disability to be included in the new Act does not alienate many Australians by focusing on medical impairment. Instead, the **focus needs to be on ways of removing the legal, social and cultural obstacles to enable greater social and economic participation**.²²

¹⁵ Mosquera, J. (2022). Defining disability and the role of the disability and the medical communities. *Theoria*, 88(3), 653-665.

¹⁶ Mosquera, J. (2022). Defining disability and the role of the disability and the medical communities. *Theoria*, 88(3), 653-665.

¹⁷ Young, E. (2022). Some people are 'disabled'. Others 'live with' or 'have a disability'. Here's the difference between identity-first and person-first language. Retrieved from <https://www.abc.net.au/news/2022-12-01/disability-language-identity-person-first/101597752>

¹⁸ Goodley, D. 2014. *Dis/Ability Studies: Theorising Disablism and Ableism*, Routledge.

¹⁹ Shakespeare, T. (2006). *Disability rights and wrongs*. London: Routledge.

²⁰ Walker, N. Toward a neuroqueer future: An interview with Nic Walker. Retrieved from <https://neuroqueer.com/wp-content/uploads/2021/07/Walker-2021-Toward-a-neuroqueer-future.pdf>

²¹ Barnes, E. (2016). *The minority body: a theory of disability*. Oxford: Oxford University Press.

²² Steele, L. (2022). Law and Disability 'Supported' Employment in Australia: The Case for Ending Segregation, Discrimination, Exploitation and Violence Against People with Disability at Work. *Forthcoming, Linda Steele, (2023) Law and Disability 'Supported' Employment in Australia: The Case for Ending Segregation, Discrimination, Exploitation and Violence of People with Disability at Work. Monash University Law Review*, 49(1).



Crucially, people with lived experience of disability need to be genuinely included in any efforts to lead or co-construct definition(s) of disability which are to be included in the new Act. Such inclusive constructions allow for the re-defining of disability as based on critical reflections of lived experience.²³

The definition of the target group in the Act will also have an educational role, to promote an understanding of disability as arising from a dynamic interaction between a health condition and environmental and personal factors, not as resulting from impairment in a deterministic way. Possible wording that could be used in the Act to define the target group:

“All individuals who experience impairments, activity limitations and/or participation restrictions arising from the interaction between an individual’s health condition/s and environmental and personal factors”.

Quality and safeguarding arrangements

QUESTION 5: How do you think quality and safeguarding arrangements should be managed by the new Act?

There is broad support for regulatory alignment across the sectors and sub-sectors that support people with disability, their families, and carers. **The development of a broader ‘wellbeing ecosystem’ for people with disability** makes regulatory sense. It is consistent with the best available evidence on good practice in responsive regulation, and is likely to support progress toward more consistent and clear requirements for service providers that aim to support people with disability. More importantly, this ‘market’ outcome is thought to be beneficial **to support a more diverse, innovative, and sustainable service ecosystem where people with disability exercise ‘choice, voice, and control’.**

The new Act should allow **recognition of other, similar quality and safety standards**, such as those established for the NDIS or the Aged Care sector. The proper calibration and convergence of regulatory instruments (including their application and penalties), in each of these sub-sectors, together with pricing and funding that covers the full cost of government requirements, should be a focus of all Australian governments. This should occur so as not to diminish or erode standards to a least common denominator. Instead, consistent with best regulatory practice, emerging arrangements should reward those service provider organisations that consistently demonstrate a strong commitment to continuous improvement and better outcomes for people with disability with less onerous (costly) regulation and recognition that is meaningful to people with disability choosing them.

Is it also important to note that recent research indicates a general lack of confidence amongst NDIS Participants that adherence to the NDIS Practice Standards adds value and that accreditation as an NDIS Registered Provider is any guarantee of quality and/or safeguarding competence²⁴. The new Act should seek to address this by supporting the development of independently verifiable information that “consumers/clients” can use to make informed decisions.

²³ Daniels-Mayes, S. (2022). Misfit in the Academy. *Redefining Disability*, 73.

²⁴ Dickinson, H., Yates, S., & West, R. (2022). Exercising meaningful choice and control in the NDIS: Why participants use unregistered providers. Retrieved from <https://apo.org.au/node/321190>



The arrangements that were developed for the NDIS Quality and Safeguarding framework, to recognise the prior evidence generated by audits under other quality auditing schemes, suggest a way forward. The work developing the NDIS Practice Standards acknowledged the positive prior experience of other jurisdictions, especially New Zealand, as well as sector feedback. However, recognising that disability is a diverse experience, and that different conditions, impairments and client groups require particular experience and skills, any attempt to create a situation where ‘anybody can support anybody’ because they are attached to a properly credentialed organisation should be avoided.

It is important to **delineate between standards that apply at the organisational level and those which apply to the workforce for disability** (which operates across multiple sectors), as well as the **competencies, capabilities and most importantly the values that are relevant to effective outcomes for people with disability**. The values, attitudes and behaviours that prevail across the broader health and human services sector are not ubiquitous in pursuing a human rights orientation that puts people with disability at the centre of everything they do. In some adjacent service sectors, attitudes that hold that ‘professionals know best’ still prevail, and facilitating their further import into the workforce for disability would deliver a worse outcome in relation to the Acts objects. For this reason, there should be continued and greater emphasis on the specific workforce capabilities that are thought to be necessary to develop a disability-specific skills ecosystem. We suggest the promotion of micro-credentials for specific conditions, impairments, and client groups.

Types of services funded under the new Act

QUESTION 6: Do you agree with the supports and services listed above? What other kinds of supports and services should be included in the new Act?

First of all, **the list of services should state “Including, but not limited to”** to ensure that the Act has longevity as service systems and supports evolve.

Other supports and services that should be included are as follows:

- Accessing, planning and receiving health supports (support and assistance to have health needs met by trained and qualified staff). This includes primary health support planning and oral health care.
- Early Intervention Support - with the NDIS, early intervention refers to those under 7 years old, however, someone may acquire or learn about a disability later in their life but can benefit from supports early on, to prepare them for the future should any significant changes occur in their life.
- Transportation, including training for independent use of public transportation.
- Behavioural support should be specifically identified
- Accessibility should include specific mention of accessibility to mental health services, a recognised problem for many people with disability who have additional mental health needs and who are excluded from mental health supports because of the negative impact of diagnostic overshadowing.
- National disability awareness education/training
- Social and relationship support



Disability Employment and Rehabilitation Services

QUESTION 7: Do you consider it necessary to retain separate provisions for employment services and rehabilitation employment program, or could they be combined?

Any decision to keep separate or to combine these two approaches needs to be informed by strong evidence.

The separation of these two aspects of employment support is emblematic of the divide between health/medical-related disability that is in a more acute phase and is acquired and longer-term disability-related employment. Addressing this has the potential to improve navigation through systems for people regardless of the origin of their disability and to move to a more functional framing of their support needs.

There is a policy need to identify the possible similarities and differences between the employment services and rehabilitation employment program approaches. Aligning with question 3 – is there redundancy that exists between these two approaches that needs to be removed?

Can these two approaches learn from each other to support improved policy outcomes?

Additional Comments and Conclusion

The new Act must not contribute to the exploitation of people with disability in any way. For example, legislation that oversees Australian disability enterprises (ADEs) allows for people with disability to be remunerated at notably lower rates than people without disability (rates as low as a few dollars per hour).²⁵

Possibilities for the new Act to support **an increased representation of disability services staff with lived experience of disability needs** to be examined. Lived experience expertise in shaping and providing disability services is increasingly respected in many countries.²⁶ However, with 24 percent of Australian disability services having reported that they employ no people with disability, strong policy measures (i.e., quotas and legislative reform) are needed to address this pressing policy issue.²⁷

Any plans for **the new Act must be led by or co-produced with people with lived experience of disability.** To what extent will policymakers with lived experience of disability be included in the development of the new Act? **‘Nothing about us without us’ applies to policymaking.**

²⁵ Wadiwel, D., Spivakovsky, C., & Steele, L. (2022). *Complaint mechanisms: reporting pathways for violence, abuse, neglect and exploitation.*

²⁶ Davies, K., & Butler, K. (2022). (Under) valuing lived experience in the disability workforce: A snapshot of Australian job recruitment. *Australian Journal of Social Issues.*

²⁷ Mellifont, D., Smith-Merry, J., & Bulkeley, K. (2023). The employment of people with lived experience of disability in Australian disability services. *Social Policy & Administration.*