



Women
With
Disabilities
Australia
(WWDA)

Winner, National Human Rights Award 2001
Winner, National Violence Prevention Award 1999
Winner, Tasmanian Women's Safety Award 2008
Certificate of Merit, Australian Crime & Violence Prevention Awards 2008
Nominee, UNESCO Prize for Digital Empowerment of Persons with Disabilities 2020
Nominee, National Disability Awards 2017
Nominee, French Republic's Human Rights Prize 2003
Nominee, UN Millennium Peace Prize for Women 2000

Ms Kate Bowmaker

Managing Director

The Social Deck

Via email: kate@thesocialdeck.com

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27 May 2023

Re: Australia's National Disability Research Partnership (NDRP)¹

Dear Ms Bowmaker

I write to you from Women With Disabilities Australia (WWDA), the award winning national Disabled Person's Organisation (DPO) and National Women's Alliance (NWA), for women, girls, feminine identifying and non-binary people with disability. WWDA is governed, run, and staffed by and for women, girls, feminine identifying and non-binary people with disability.²

Following up on our recent phone conversations, WWDA writes to express our deep concern at the recent request from The Social Deck (consultancy service for and on behalf of the National Disability Research Partnership (NDRP)) to a vast array of stakeholders to provide 'Feedback' on the draft research agenda of the NDRP, which "*will help to guide what research is funded by the NDRP over the next 10 years.*"³ As you are aware, the NDRP is a key initiative under Australia's Disability Strategy (ADS) 2021-2031 and is instrumental in building the evidence base for the ADS to help to improve outcomes for people with disability. The ADS is the national policy document for implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD), and it follows that the evidence base must assist in CRPD

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implementation. WWDA recognises that The Social Deck has recently been engaged by the NDRP to manage the feedback on its behalf on the current draft research agenda of the NDRP.

As detailed on the NDRP website: *“The draft research agenda sets out broad research topics based on findings from a research project and initial consultation undertaken by the Centre for Disability Research and Policy and the Centre for Disability Studies at the University of Sydney, together with a large group of researchers and community organisations.”*⁴

WWDA was involved in this research project and initial consultation process, and provided significant contribution, particularly stressing the imperative for the research agenda of the NDRP, to reflect and be consistent with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and Australia’s Disability Strategy (ADS) 2021-2031.⁵ WWDA specifically provided detailed input and evidence-based information to the first “research project and initial consultation process” to affirm the requirement of the NDRP to be gendered (as per Article 6 of the CRPD) and intersectional (as per the entirety of the CRPD as an intersectional human rights treaty, and also the ADS 2021-2031). WWDA is also aware that there were some problems with the research project and initial consultation (undertaken by the Centre for Disability Research and Policy and the Centre for Disability Studies at the University of Sydney), which eventually led to WWDA terminating our role as a member of an advisory committee for this work. I am happy to elaborate on this further should it be required and provide documentary evidence as to why WWDA elected to cease our involvement in the work.

The limitations of this work (undertaken by the Centre for Disability Research and Policy and the Centre for Disability Studies at the University of Sydney), and subsequent work undertaken by the NDRP following the first “research project and initial consultation process”, is highlighted by the NDRP in its 2022 published report entitled: *‘National Disability Research Partnership: Preliminary Research Agenda’*.⁶

WWDA understands that the current engagement process by the NDRP (which Social Deck is managing) involves a lengthy online survey, and also an Engagement Paper, both publicly released in late April 2023.⁷ The current NDRP draft research agenda, provides 12 ‘priority’ research areas. We understand that the Engagement Paper and Survey are drawn from and based on the *‘National Disability Research Partnership: Preliminary Research Agenda’* report. This report sets out the ADS 2021-2031 outcome areas, and then puts ‘research questions’ underneath. However, the Engagement Paper and the Survey, identifies 12 priority areas, (rather than the seven ADS Outcome areas) which makes it confusing.

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As discussed with you recently, it is beyond the capacity of WWDA to provide detailed feedback and responses to the lengthy survey and/or the Engagement Paper. This would be far too labour intensive, given the number and range of concerns we have.

We are concerned with the 12 'priority' research areas, and many of the 'statements' and 'questions' provided under each of these areas. In this context, we therefore outline just some of our **key** concerns with the current NDRP draft research agenda. These are provided below in no particular order of priority.

1. The draft Research Agenda refers throughout to 'people with disability' as though disabled persons are a homogenous group. This is not consistent with an intersectional human rights model or approach. People with disability in Australia come from a range of backgrounds, lifestyles, beliefs and communities. They may be Indigenous or come from culturally and linguistically diverse communities. They may have a faith, or not; be married, divorced, partnered, or single; gay, lesbian, bisexual, feminine-identifying, non-binary, transgender or intersex; parents, guardians, carers, and friends. They may or may not be in paid work, or they may or may not be engaged in education and training. Each of these contexts can affect how, when, why, and in what form a person with disability accesses, receives and/or is denied, services and supports, and how or if they are included in social, political, cultural and economic opportunities and participation in community life. In this context, the draft Research Agenda should make it clear that (consistent with the ADS 2021-2031) *"Policy responses and strategies which assume the experience and impact of disability is the same, can fail to take into account intersectional impacts disproportionately affecting groups of people with disability."*
2. The 12 'priority' research areas are confusing, with no clear rationale as to why these areas are deemed to be priorities, nor how they reflect, for example, concluding recommendations to Australia from the human rights treaty monitoring bodies (not just the CRPD). The 12 priorities do not successfully get to the human rights elements in these priorities. In fact, they maintain the policy and funding framework status quo, rather than engaging in the transformation, based on evidence, that needs to occur to fulfil CRPD obligations. There is no engagement with the CRPD Concluding Observations, which provide Australia with a clear roadmap for next steps in realising human rights. It is also widely acknowledged (including by the Disability Royal Commission, for example) that implementation of the international human rights treaties (to which Australia is a party) is not mutually exclusive. In the context of persons with disability, they are expected to be



viewed and implemented as complementary mechanisms through which to create a holistic framework of rights protection and response.

3. For example, Priority Area 6 as currently stated in the draft Research Agenda is *“Upholding and promoting rights of people with disability”*. Given that the NDRP is framed by and within the CRPD and the ADS, the ‘Upholding and promoting rights of people with disability’ should be embedded in any/all of the research priority areas of the research agenda.
4. WWDA is deeply concerned that the work to date from the National Disability Research Partnership (NDRP) in regard to the development of a 10-year NDRP Research Agenda, demonstrates an institutional failure to understand the fundamentals of the CRPD (and the other international human rights treaties to which Australia is a party); the policy context and displays minimal rigour and engagement with the existing evidence base. For example, many of the proposed research “questions” (both within the Engagement Paper, Survey, and the *‘National Disability Research Partnership: Preliminary Research Agenda’* report), replicate existing research. In priority area 1 (Research about employment of people with disability) the draft research agenda has a focus on “barriers”. There has already been a substantial amount of research on barriers to employment for people with disability in recent years (eg: The national Willing to Work Inquiry; the development of the National Disability Employment Strategy; the AHRC Includability Project; the extensive consultations undertaken as part of the two-year consultation process for the development of the ADS; just to name a few). The Disability Royal Commission has also examined this area through its public hearings; commissioned research, evidence-based Submissions and much more.
5. There are many problematic research “questions” proposed, both in the Engagement Paper and the *‘National Disability Research Partnership: Preliminary Research Agenda’* report. For example, to cite just a few:
 - “What models of housing work best, including to promote the inclusion of people with disability with mental health issues?”
 - “Are current guardianship systems upholding and protecting the rights of people with disability? How should they be reformed?”
 - “Are current systems for substitute decision-making protecting and upholding the rights of people with disability? How could they be reformed?”



- “What are the social and economic benefits of inclusion of people with disability?”
 - “What are the transport needs of children and adults with disability and how can they be addressed?”
 - “How can family violence against women and girls with disability be reduced?”
6. The CRPD Committee has made it clear that “guardianship and substitute-decision making” regimes are not CRPD compliant, violate human rights, and have repeatedly recommended that Australia abolish these systems. The CRPD Committee, CEDAW General Comment 35, the current *National Plan to Reduce Violence Against Women and their Children (2022-2032)*, the CAT Committee, along with DPOs such as WWDA – clearly articulate the language of “gender-based violence” – rightly recognising that for example, terms such as “domestic violence, family violence, intimate partner violence”, exclude cohorts such as disabled women and girls. The CRPD Committee (as per CRPD Article 19) has also made it clear, as have other international human rights treaty monitoring bodies, that terms such as “models of housing” in the context of disabled persons, are outdated concepts, and that persons with disability have the right to freely make choices about where and with whom to live on an equal basis with others and to receive the disability and mainstream community supports required to ensure full participation and inclusion in all aspects of society. The proposed question “*What are the social and economic benefits of inclusion of people with disability?*” is profoundly offensive, and certainly does not demonstrate an understanding of the fundamental human rights of people with disability. WWDA would therefore be deeply concerned if the NDRP Research Agenda prioritised and/or funded research that is clearly inconsistent with Australia’s international human rights obligations, and the intent of national policy frameworks such as the ADS and the National Plan to Reduce Violence Against Women and their Children.
7. It is unclear as to whether the work from the Disability Royal Commission (DRC) to date, has been used to inform any of the 12 proposed research areas. We would strongly recommend that the ‘priority’ research areas for the NDRP Research Agenda, are not finalised until the release of the Final Report of the DRC. In addition, it must be recognised that there are other significant reviews etc currently being undertaken where the findings/recommendations must be utilised to inform the research priorities of the NDRP Research Agenda. Just some current examples include: The National Disability Insurance Scheme Review; and the Human Rights Framework Parliamentary



Inquiry. WWDA strongly recommends that the NDRP Research Agenda “priorities” are not finalised until the completion of these critical processes.

8. The draft NDRP is not gendered in any way, which is of serious concern, given the obligations under Article 6 of the CRPD, along with CRPD General Comment 3. The lack of a gendered lens and approach is also concerning given the context of the Australian Government’s current work to develop a National Gender Equality Strategy, and its emphasis on the requirement for Gender Responsive Budgeting (GRB) across Australian Government policies and programs.
9. There is no clear evidence of an intersectional approach within the current 12 ‘priority’ research areas. The ADS (and its targeted action plans), the DRC, the National Plan to Reduce Violence Against Women and their Children (2022-2032) – to name just a few – re-iterate the importance of and embed intersectionality in their frameworks.
10. The draft NDRP Research Agenda does not use human rights language and in parts, reverts to a medicalised and diagnostic approach. For example, terms such as “mental health problems”; “mental health issues”; “vulnerable” are outdated concepts that not only reflect a medical approach, but also imply a deficit in the individual. As the Special Rapporteur on Disability (Gerard Quinn) has recently reiterated, (as has WWDA in many of our Submissions to the DRC and other processes) people with disability are not inherently “vulnerable”. It is more often than not, that it is ableist systems, structures and environments that place people with disability more “at risk” of violence, abuse, exploitation and neglect, and other forms of discrimination and oppression.
11. It is also concerning that the Engagement Paper and the ‘*National Disability Research Partnership: Preliminary Research Agenda*’ report continues to imply that people with intellectual disability are the only group that are affected by particular issues and therefore research only needs to focus on this group in the context of that issue. This completely ignores how systems impact a broad range of people with disability and not just one diagnostic group. For example, in the criminal justice question, there is an implication that research is only relevant to people with intellectual disability. This is replicated in a number of the other “research priority areas”. It beggars belief that the proposed research “question” on the criminal justice system, does not even mention First Nations persons with disability. Confining proposed “research” to intellectual disability simply maintains the historical approach to funding disability services that targeted people with intellectual disability. This does not mean that certain cohorts of disabled persons should not be

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prioritised in potential research, but as the current NDRP Research Agenda stands, “people with intellectual disability” are the only ‘diagnostic group’ that are mentioned. The CRPD does not work this way; it transcends policy and funding frameworks.

12. There is nothing in the draft NDRP Research Agenda that prioritises, nor aims to examine, the many egregious human rights violations that people with disability in Australia continue to experience and be at risk of. Many of these violations remain facilitated and permissible by current laws. Just some examples include:

- Segregation of people with disability in all settings and contexts.
- The denial of legal capacity and equality before the law.
- Forced treatments and restrictive practices (including for eg: forced ECT, authorisation of psychosurgery; forced sterilisation; chemical, mechanical, physical, environmental restraint and seclusion; enforced medical correction of intersex variations).
- Sexual and reproductive rights violations (including for eg: forced sterilisation; forced contraception; menstrual suppression; forced abortion; forced/coerced marriage; forced anti-androgenic treatments; sex ‘normalising’ medical interventions).
- Indefinite detention and deprivation of liberty of people with disability.
- Discrimination against migrants and refugees with disability.
- The over-representation of people with disability living in poverty.
- The lack of an adequate standard of living and social protection for people with disability.
- The lack of full participation of people with disability including through their representative organisations, in all matters that affect them.
- The lack of a national Redress and Reparation Scheme for people with disability who have been subjected to egregious human rights violations.
- The increase in applications (and approvals) for guardianship and financial management of NDIS participants since the inception of the Scheme.
- The need to reform Commonwealth, State/Territory laws to ensure compliance with the CRPD, including addressing the common law doctrine of *Parens Patriae*.

13. Given that the NDRP Research Agenda is for a ten-year period, we would expect, and demand, that these egregious human rights violations are prioritised within the NDRP and its 10-year Research Agenda. These areas have been the subject of ongoing recommendations by the



Committee on the Rights of Persons with Disabilities and the research agenda should build the evidence base for Australia to respond to these recommendations.

14. The *'National Disability Research Partnership: Preliminary Research Agenda'* report states that *"the NDRP Working Party is considering using a modification of the Child Health and Nutrition Research Investments (CHNRI) method to set the priorities."*⁸ WWDA is confused and perplexed by this, given that the CRPD provides a clear roadmap for advancing and realising the human rights of disabled people. We question why the NDRP would not be utilising the CRPD, the ADS Outcomes Framework, and also the CRPD Human Rights Indicators. As clearly articulated by the Office of the United Nations High Commissioner for Human Rights (OHCHR), *"Human rights indicators on the CRPD are key to facilitating understanding and implementation of the Convention's provisions. They serve to give guidance on actions and measures to be taken in implementing the CRPD and facilitating assessment of this progress."*⁹

15. The NDRP is a critical initiative that MUST be grounded in and framed by human rights and reflect and be responsive to Australia's international human rights obligations under the seven international human rights to which Australia is a party, including the UN Declaration on the Rights of Indigenous Persons (UNDRIP), which Australia endorsed in 2009. We are very aware that Australia's reputation in relation to its international human rights obligations is in jeopardy.¹⁰ We further note that Australia's Attorney-General, the Hon Mark Dreyfus KC, MP, has reiterated that: *"The Albanese Government believes all people are entitled to respect, equality, dignity and the opportunity to participate in the social, cultural and economic life of our nation. But principled statements about the importance of human rights are not enough – the onus is now on us, the new Albanese Labor Government, to make the necessary changes to enshrine these values in the laws of our nation."*¹¹

WWDA understands that the NDRP Research Agenda will be "handed over" to a new independent organisation and Board, once the NDRP transitions to this process. We assume that this will be an open tender process but are not clear as to the details. We are very concerned that the current NDRP Research Agenda (with its 12 "priority research areas") is flawed, does not reflect Australia's international human rights obligations, nor several of Australia's national policy frameworks and initiatives to advance the human rights of people with disability. We therefore wish to have the opportunity to discuss our concerns with the Minister for DSS, the Hon Amanda Rishworth, and relevant senior personnel within DSS, to expand on the issues we have raised in this letter. Furthermore, we believe it may be useful for DSS to

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convene a meeting with Disabled People's Organisations (DPOs) and Disabled Peoples Representative Organisations (DRO's) to discuss the issues we have raised, in more depth.

In closing, WWDA is of the view that it is critical that the NDRP and its proposed National Research Agenda, to have the confidence and backing of people with disability, including through their representative organisations. As things currently stand, we are concerned that this will not be the case, unless changes are made.

We look forward to your earliest response.

With kind regards

Carolyn Frohmader
Executive Director

Finalist, 100 Women of Influence Awards 2015
Australian Human Rights Award (Individual) 2013
State Finalist Australian of the Year 2010
Inductee, Tasmanian Women's Honour Roll 2009
Australian Capital Territory Woman of the Year Award 2001

¹ See: <https://www.ndrp.org.au/about>

² WWDA uses the term 'women and girls with disability', on the understanding that this term is inclusive and supportive of, women and girls with disability along with feminine identifying and non-binary people with disability in Australia.

³ <https://www.ndrp.org.au/get-involved>

⁴ <https://www.ndrp.org.au/get-involved>

⁵ It must also be stated that the ADS 2021-2031, was developed within the context of a Federal Liberal Government, which limited the ADS in several respects. For example, the ADS does not provide specific outcome area nor policy priorities regarding the sexual and reproductive rights of persons with disabilities; has limitations in relation to domestic implementation of the CRPD, and so on.

⁶ Available at: <https://www.ndrp.org.au/researchagenda>

⁷ <https://www.ndrp.org.au/get-involved>

⁸ See page 33 of the 'National Disability Research Partnership: Preliminary Research Agenda' (2022); Available at: <https://www.ndrp.org.au/researchagenda>

⁹ <https://www.ohchr.org/en/disabilities/human-rights-indicators-convention-rights-persons-disabilities-support-disability-inclusive-2030>

¹⁰ <https://www.thesaturdaypaper.com.au/news/law-crime/2023/05/20/exclusive-un-set-sanction-australia-over-human-rights-abuses#hrd>

¹¹ THE HON MARK DREYFUS QC MP, Attorney-General, "Restoring a human rights-based approach"; Annual Castan Centre for Human Rights Law Conference; 22 July 2022.

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