SUBMISSION ON THE NATIONAL DISABILITY STRATEGY, STAGE 2 POSITION PAPER

20 October 2020

Contents

Attention:

National Disability Strategy Governance and Engagement Section
Department of Social Services
GPO Box 9820
Canberra, ACT 2601

Overview

Thank-you for the opportunity to provide feedback regarding the National Disability Strategy (NDS) Stage 2 Position Paper. I have worked on disability-inclusion projects for the University of Sydney (co-sponsored by the Queensland Department of Communities, Disability Services and Seniors and the Queensland Reconstruction Authority) and Queenslanders with Disability Network. I have also been a regular supporter and volunteer for several disability support and advocacy groups including MS Queensland and Emerge Australia. Furthermore, I have conducted academic research on international/United Nations Convention-related human rights as well as have worked in several strategic planning roles across the public sector.

I strongly support Mahatma Gandhi's quote that "the true measure of any society can be found in how it treats its most vulnerable members (The Theosophical Society, 2020)." As per the findings of Australia's current Disability Royal Commission, people with disability (PWD) comprise some of Australia's most vulnerable members. Therefore, I urge the Australian government to develop and implement a robust, effective person-centred NDS that includes the following:

My 7 key recommendations

1. The NDS' oversight should be the key responsibility of either the Premier and Cabinet or an independent body such as the Human Rights Commission. If the NDS is under the Dept of Social Security, disability may risk becoming marginalised as 'just a social security' issue and all other related issues impacting people disability, e.g. transport, housing, employment, water, energy policy, may not be adequately addressed.
2. Has meaningful, clear key performance indicators. What doesn't get measured, rarely gets managed.
3. All government agencies, federal, state and local, are to be held accountable to comply with and annually report on the NDS.
4. Provide sufficient resourcing and funding to develop and implement the strategy across all government agencies.
5. Explicitly include 'invisible disabilities', e.g. ME/CFS, fibromyalgia, dysautonomia, etc; as disabilities. 'Disability' too often is translated to mean visual/hearing impairment, wheelchairs and 'high-profile' illnesses (e.g. cancer). For starters, redesign the blue 'disability symbol' to include people with invisible disabilities.
6. Prioritise reaching out to PWD facing multiple marginalisation/disadvantage, e.g. women, youths, elderly people, homeless people, Indigenous people, Culturally And Linguistically Diverse (CALD) and refugees, incarcerated people, etc; Often their voices are under-represented and/or missing from public consultations regarding PWD.
7. Include PWD meaningfully as full decision-makers on decision-making bodies, not just treat them as 'external stakeholders' to be consulted.

Vision

Question 1: During the first stage of consultations we heard that the vision and the six outcome areas under the current Strategy are still the right ones. Do you have any comments on the vision and outcome areas being proposed for the new Strategy?

Involve and engage

Person-centric

I agree with page 5 that the new NDS should be person-centric in that the policy architecture should revolve around creating the structures and practices through which PWD can understand and exercise their rights across all domains.

Invisible disabilities, including housebound/bedbound

Too often disability is misinterpreted narrowly to mean the more visible and recognised conditions such as visual and hearing impairment and/or people in wheelchairs. People with invisible disabilities, particularly people who are housebound and/or bedbound, must be engaged in order to obtain a more comprehensive understanding of the needs of PWD. Often these cohorts are highly vulnerable yet highly marginalised due to inaccessibility and nonrecognition. Therefore, I recommend that 'disabilities' also include people who suffer from energy-limiting conditions such as endometriosis, spinal cord injuries, auto-immune disorders, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), dysautonomia, fibromyalgia, Ehlers-Danlos Syndrome and many more (Hale, Benstead, Lyus, Odell, & Ruddock, 2020, pp. 76-77).

'Disability' definition

Due to the above-mentioned 'stereotype' of disability, often many people who have chronic illnesses or injuries end being overlooked in consultations, even although they do conform to the definition of disability, as per the Convention on the Rights of People with Disabilities (CRPD).

Consequently, to fully involve and engage such 'uncertain' and therefore missing yet bona fide PWD, I recommend that the Strategy explicitly reflect the CRPD's Article 1's definition of disability:

"Persons with disabilities **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."

Outcomes

Concrete, SMART measures needed

The outcomes appear to be too vague and do not propose concrete, Specific, Measurable, Achievable, Realistic, Time-Based (SMART) measures. It is unclear as to how these outcomes and measures would relate to the United Nations review of Australia under the CRPD. Concrete measures are needed to consistently drive the Strategy across government and jurisdictions to effectively deliver solid, meaningful outcomes (Davy et al., 2019, p. 26).

Inter-related and integrated

It is unclear as to whether and the extent that the Strategy recognises the 6 outcome areas as inter-related and integrated. In my belief, these 6 areas should be explicitly recognised as inter-related and integrated.

Guiding principles
Question 2: What do you think about the guiding principles proposed here?

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

I agree with the above-mentioned principles but would also add:

1. 'Involve and engage **meaningfully** to PWD' – too often engagement is a tokenistic effort. 'Meaningfully' would include having PWD engaged as full decision-makers, not just external stakeholders.

2. 'Priority populations' should be defined according to **degree of vulnerability** physically, mentally, emotionally, financially and spiritually. Using a vulnerability index, similar to QLD's vulnerability in disasters framework (Department of Communities, 2016), I anticipate that such populations would include PWD who are also: housebound/bedbound, homeless, severely incapacitated, youths, elderly, Indigenous, from Culturally And Linguistically Diverse (CALD) backgrounds, refugees, incarcerated or LGBTQI.

   For example, I support prioritising better and early intervention in healthcare particularly for youths with disability to help maximise chances of reaching their full, lifelong potential, health and wellbeing.

3. **'Person-centric'**, as outlined on the position paper's page 5, as opposed to institution/organisation-centric. In practice, this would be reflected in "greater availability of individualised funding and services that meet individualised needs rather than organisation and system needs (National People with Disabilities and Carer Council, 2009, p. 22)" such as an individualised support packages.

4. **'Integrated and holistic'** – policy and programs should be designed with an integrated and whole-of-system, networked approach so that linkages between programs and organisations are fully addressed. This would avoid organisational siloes, gaps and expensive duplication. Research such as that by Elinor Ostrom has identified the importance of whole-of-system integration and networks for fostering community resilience (Aligica & Tarko, 2014).

   To ensure its effectiveness, the Strategy cannot be developed and implemented in isolation. It must be planned and implemented in alignment with other government initiatives and reviews, including (but not limited to) the findings from the Disability Royal Commission and those listed in the Shut Out report such as:

- National Homelessness Strategy
- Disability Standards for Education (2005)
- Disability Standards for Accessible Public Transport (2002) (National People with Disabilities and Carer Council, 2009, pp. 62-63).

Similarly, a review of inter-related legislation should be conducted to clarify and improve upon the existing legislative gaps across and within all levels of government. Legislation includes not only the more obvious 'disability-related' legislation such as the Disability Discrimination Act and the NDIS Act but also mainstream, 'non-disability' legislation such as those pertaining to the environment, manufacturing, the built environment and taxation.

5. **'Equity'** – all aspects of the Strategy should be developed to achieve equity, not equality, for PWD and recognise the systemic and cultural disadvantages faced by PWD. For example, the Shut Out report acknowledged the large number of submissions that expressed frustration regarding the "irretrievably broken and broke, chronically under-funded and under-resourced, crisis driven"(National People with Disabilities and Carer Council, 2009, p. 19) nature of disability services and programs and that the system is "difficult to navigate, excruciatingly slow and unresponsive (National People with Disabilities and Carer Council, 2009, p. 20)." This dismal situation of disability services and programs reflects the lack of equity for PWD within Australia. This must be remedied by recognising and working towards promoting and ensuring equity for PWD across all policies, strategies and programs.

6. 'Both short-term and **long-term/future-oriented'** – Too often strategies are based upon people's narrow understanding and assumptions of current and past circumstances. Meanwhile, too few are based upon projections of the likelihood of different circumstance. This is akin to people during the typewriter era developing strategies based upon an assumption of more typewriters, rather than computers.

I therefore recommend including a principle that recognises that the Strategy should be developed and implemented based upon future trend projections regarding the next 30 years, such as climate change impacts and a large influx of climate change refugees, the end of peak oil and the predominance of populations living in urban environments.

Increased focus on community attitudes
Question 3: What is your view on the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas?

Not just attitudes but also behaviours, practices and rules

I agree that community attitudes should be an area of focus. But the focus should not just be on what people 'think' but also how those attitudes are reflected in actual behaviours, practices and rules.

I agree that workplaces are not sufficiently accepting of PWD. Examples:

- Hours: requirement for PWD to be able to work at least 15 hours/week. Many PWD do not have sufficient capacity to do so. Workplaces should be open to employing PWD for under 15 hours/week.
- Work environment: adjustments not just in terms of mobility and equipment, but also noise, chemicals, light-sensitivity.
- Location: work-from-home needs to be better accommodated.

Foster, monitor and enforce

The statement that the Strategy is to "Foster" ongoing attitudinal change must be strengthened. The Strategy also needs to add 'monitor and enforce'. 'Foster' suggests too passive an approach. Unless the strategy is accompanied with the following, it is likely not to go far.

- Strong legislation
- Strong governance
- Regulation
- Monitoring/reporting/data collection
- Adequate, enduring resourcing
- Strong enforcement of anti-discrimination legislation.

Strengthening accountability
Question 4: How do you think that clearly outlining what each government is responsible for could make it easier for PWD to access the supports and services they need?

1. ***All* government departments** at local, state and federal levels, not just disability supports/services (e.g. health and NDIS), should include disability inclusion as a key facet of their policies and projects, including business case evaluation and funding criteria (Davy et al., 2019, p. 28).

    For example, the following mainstream 'non-disability' areas also affect PWD:

- Environment – e.g. biodiversity is vital to medicine supply chain. Many medicines are developed using plants.
- Climate change
- Infrastructure
- Manufacturing – toxic chemicals used in manufactured products disproportionately worsen the health of PWD who have immune-compromised systems, e.g. people with multiple chemical sensitivities, asthmatics.
- Taxation
- Immigration and Foreign affairs – many immigrants, refugees and asylum seekers have disabilities
- Housing – e.g. building codes, zoning for housing should not be in high-risk/high-pollution areas as PWD are more vulnerable when disasters strike, pollution leaks, etc;

The above areas also impact people with disabilities and therefore the respective government agencies should be accountable.

It is essential that clear outlining of each government's roles and responsibilities and accountabilities are under the Strategy. Furthermore, each government agency must be adequately resourced to carry out their duties effectively. These accountabilities must also be enforceable (Davy et al., 2019, p. 27). An absence of clear accountability roles results in siloing of disability policy and programs, serious gaps and/or overlaps between agencies.

2. **Coordination via centralised agency** – While all government departments should develop and implement disability-inclusion, the University of NSW review report acknowledges "an absence of an effective 'centralised agency with responsibility for coordination of implementation of the NDS (Davy et al., 2019, p. 25)." Therefore, the Strategy's development, implementation and monitoring must be centrally coordinated under one organisation that sits within the Department of Prime Minister and Cabinet or is an externally, independent authority, such as the Human Rights Commission that is sufficiently resourced (Davy et al., 2019, p. 26).

3. **Strong, transparent and effective governance, who is governing and who are their key advisors?** – A key facet for strengthening accountability and effective Strategy development and implementation is establishing strong, clear and transparent governance arrangements, including balanced representation on governing bodies and whom they consult for advice. Effective governance also requires solid review and redress processes in the event that governance is ineffective.

   Of concern in the ME/CFS community is the fact that severely limited expert advisory input exists regarding the interpretation of NDIS assessment guidelines. Apparently, this limited advice for decision-makers has resulted in misinterpretation of the clinical basis for NDIS eligibility. Consequently, an enormous proportion of people with ME/CFS are ineligible to access the NDIS despite, in many cases, decades of enduring severe disability (Hallmann, 2018).

4. **Measuring and reporting outcomes** – The extent to which needs of PWD are fulfilled should be a standard KPI within *all* government programs, projects as well as in *all* executive and staff KPIs.

   Unless people are held accountable as both individuals and as a team, progress on disability inclusion may risk being treated simply as 'optional'.

Question 5: How do you think the Strategy should represent the role that the non-government sector plays in improving outcomes for PWD?
(Examples of the non-government sector include big, medium and small businesses, community organisations, employees of these businesses, private research, investment organisations and individuals.)

1. The Strategy should include the non-government and business sectors as playing a central role to government in improving outcomes for PWD.

2. **Legislation:** The Trade Practices Act should be amended so that Duty of Care should specifically and explicitly call out that businesses have a duty of care to PWD.

3. **Funding and accreditation criteria** - Similarly, legislation, accreditation and funding criteria for community organisations should include clauses that specify that needs of PWD are to be met as a condition of compliance.

Measuring outcomes and reporting
Question 6: What kind of information on the Strategy's progress should governments make available to the public and how often should this information be made available?

1. The Ministerial Council should release an annual National Disability Report and table it in Parliament annually.

   Assuming that all federal Ministers are members of the Ministerial Council, I agree that the Ministerial Council, with the Department of Prime Minister and Cabinet as the lead agency, should be the ultimately accountable organisation for the planning and implementation of the Strategy, not the Department of Social Services (DSS).

   To ensure that the Strategy is managed effectively, I also agree with the Shut Out 2009 report's recommendation that "creation of an Office of Disability to coordinate efforts across portfolios and between levels of government (National People with Disabilities and Carer Council, 2009, p. 8)." Furthermore, the Office of Disability should be within the Department of Prime Minister and Cabinet as the lead agency to ensure full, cross-departmental coordination and accountability. If the Office were under the Department of Social Security, it may run the risk of being 'side-lined' as merely a social security matter and/or beheld primarily to the priorities of the Minister for Social Security.

2. The progress report should be published every year.

3. Standard framework and benchmarking - The report should analyse progress towards outcomes against the outcomes framework and identify the contribution of government policies/programs towards achieving these outcomes. The framework should include meaningful, Specific, Measurable, Achievable, Realistic and Time-based KPIs.

   Standardised benchmarking of performance within business, non-government and public sector should be conducted to measure the extent to which these entities fulfil their obligations in improving outcomes for PWD.

   Unless there is a standardised framework and benchmarking, it would be difficult to compare performance and recommend requisite improvements. What doesn't get measured doesn't get managed effectively.

4. Individual agencies - Furthermore, each government agency, not just the Ministerial Council, including government-owned corporations, should also report their agency's individual progress. All agencies should be benchmarked according to the standard reporting framework.

If the Council is the only body that is held accountable, the individual agencies might just pass off accountability to the Council and not own their respective roles in supporting the Strategy.

Collecting data and evaluating policy and programs

I agree with the points that COAG's Australian Data and Digital Council establish a National Disability Data Asset (NDDA). The NDDA should include de-identified Commonwealth and services data, NDIS data and service system data from states and territories.

All government agencies, not just the NDIS, health and social services

However, similar to my response to Question 4, the data should not be constrained to just the NDIS, health or social services data but also include data from all other government departments (local, state and federal) to ascertain the extent to which PWD are supported by the respective agency.

For example, to what extent do all infrastructure projects include the needs of PWD? To what extent are all infrastructure projects avoiding use of chemicals that damage the health of PWD?

I appreciate that undertaking this data collection would be substantial. To begin with, all agencies should conduct an 'as-is' baseline audit to ascertain 1) percentage of employed staff and contractors who are PWD. 2) percentage of their customers/clients who are PWD and 3) how each of their projects support PWD.

Data collection quality

I am aware that current Australian government data about PWD is significantly lacking. For example, apparently the Commonwealth gov'ts National Minimum Data Set that is used for planning disability services, e.g. transport, is very poor and out-of-date. Consequently, only about 10 percent of disabled people are supported under the NDIS. Therefore, I recommend that the Strategy investigate ways to improve the National Minimum Data Set data collection methods to ensure that PWD are fully accounted for and respective government policies and programs are fully informed.

Adequate funding for data collection and evaluation

Data collection to measure the Strategy's implementation progress is essential for tracking implementing gaps and informing future improvements. The funding must be adequate and also monitored to ensure that the funding is, in fact, devoted to data collection and evaluation, rather than siphoned off to other areas, as apparently has been the case according to the Productivity Commission (Davy et al., 2019, p. 35).

Evaluating policy and programs

I agree that the new Strategy include a commitment from governments to undertake policy and program evaluations re: PWD. *Furthermore, funding for governments should be tied to the extent to which they fulfil the needs of PWD.* Without tied funding, the policy and program evaluations are likely to be ineffective and tokenistic at best.

Putting policy into action to achieve outcomes for all PWD

I agree with the proposals in this section. A coordinated approach is vital and using a standard outcomes framework can assist in coordinating the desired outcomes and related actions.

All politicians, executives and staff

However, simply having a framework will not be sufficient unless all politicians, executives and staff performance KPIs are also aligned and include specific KPIs to fulfil the needs of PWD. In my experience in embedding sustainability KPIs and customer-centric KPIs across QLD government departments, unless individual staff performance KPIs are aligned, little action occurs and ends up being only an 'optional' activity adopted by those who have an intrinsic, personal interest in that outcome.

Targeted Action Plans

Question 7: What do you think of the proposal to have Targeted Action Plans that focus on making improvements in specific areas within a defined period of time (for example within one, two or three years)?

In principle, the Targeted Action Plans (TAP)sound like a good idea in that they would focus on improvements for specific, defined periods of time. However, to avoid 'short-termism' at the expense of meaningful, long-term progress, these Targeted Action Plans should also be linked to:

1. A long-term, 30-year vision and its goals.
2. The TAPs should be integrated with one another and demonstrate whole-of-system integration. For example, social security (e.g. Centrelink) payments impact housing affordability, health and multicultural policies – and vice versa. Similarly, infrastructure policy and planning impact water management, which also indirectly impacts health among PWD.
3. Each of the TAPs should have integrated KPIs that link to both the overall evaluation framework and each individual agency's KPIs.

Population and climate change forecast assumptions

All of the TAPs as well as the Strategy should be based upon both short-term and long-term PWD population forecasts. Given that Australia's projected mobility-related PWD population alone will reach around 4.7 million over the next 40 years (Wiesel, 2020, p. 8), the overall PWD will likely be even greater once non-mobility-related disabilities are included. Furthermore, climate change-related destruction and climate change refugee intakes will likely further increase Australia's future PWD.

> **FUTURE POPPULATION GROWTH AMONG PEOPLE WITH MOBILITY-RELATED DISABILITY**
>
> Extrapolating from Australian Bureau of Statistics (ABS) data and population projections, the Centre for International Economics (CIE) estimated that the number of Australians with a mobility-related disability will increase from 2.9 million in 2018 to around 4.7 million people over the next 40 years, due to population growth and an ageing population (Wiesel, 2020, p. 8).

Engagement plan

Question 8: How could the proposed Engagement Plan ensure PWD, and the disability community, are involved in the delivery and monitoring of the next Strategy?

PWD as full decision-makers, not just 'feedback-only' stakeholders, in planning, delivery and monitoring

PWD should be included as not just stakeholders to be 'engaged with' but should be involved meaningfully as full decision-makers on the respective government committees in not only delivery and monitoring, but also the planning phases.

Lessons learned from other disadvantaged groups seeking equity

Achieving disability-inclusivity shares similar challenges experienced by other disadvantaged groups in achieving equity, such as gender-equity, First Nations communities' drive to 'Close the Gap.' I recommend that the Strategy examine lessons learned from these other 'equity-embedding' initiatives to ascertain what approaches may help inform the Strategy's similar challenges in tackling and overcoming discrimination and inequity. My key concern is that Australia's 'Closing the Gap' strategy has achieved only minor progress and that disability targets were removed from the recent revised targets (Harris, 2020b; Kelly, 2020a). Given the growing population of PWD, Australia cannot afford to repeat similar mistakes in the disability field.

Workforce development

Equity employment targets

To the above-mentioned end, similar to other employment equity approaches, there should be employment targets that ensure that at least 25% of the decision-makers are PWD to be commensurate with the fact that 1) the current PWD population is 20% of the Australian population and that 2) the PWD population will likely increase to about 25% by 2050.

The employment targets should not only apply to the NDIS and other disability services. These targets should also apply to all other government agencies since, as per my points regarding Question 4 (Accountability) since all government agencies impact PWD.

To only narrowly focus workforce development on the NDIS and the more 'obvious' government agencies (e.g. Social Security, Health), would ignore how other government agencies, policies and programs impact PWD. To sufficiently address the needs of PWD, we need a whole-of-government integrated approach – otherwise we will only achieve siloed and therefore limited, marginal success. Nothing about us, without us.

Answers to participant-specific questions:

1. What has changed for you or in your community over the past 5 years?

   a. Increased recognition of ME/CFS. The federal government had finally committed $3M to research (first time ever) on ME/CFS and all the 3 major federal parties committed policies to the illness (first time ever).
   b. Availability of telehealth, due to COVID-19, means greater access to health services.
   c. Media visibility of PWD (e.g. ABC journalist)

   d. Increased risk of climate change risk, e.g. bushfires → worsening health (e.g. respiratory). But DIDRR prep.
   e. Closing the Gap targets lost disability target.
   f. NDIS only available for about 10%

2. What are the things you want to see improved in your life or for PWD and why?

Systemic change

I would like to see improved equity for PWD as evidenced in systemic change including:

   a. **UNCRPD-related rights protection, especially access to legal services** – I support the Shut Out report's recommendation for "a comprehensive legislative and policy review of Commonwealth and state and territory legislation and policies to remove conflicts with the UN Convention on the Rights of Persons with Disabilities" and that "the powers of the Human Rights Commissioner should be extended to investigate cases without the need for an individual complainant, or that advocacy groups should have the right to bring cases on behalf of a group of individuals (National People with Disabilities and Carer Council, 2009, p. 17)."

   In particular, I recommend that "PWD people with disabilities have a legislated right to the aids, equipment and technology they require for daily living (National People with Disabilities and Carer Council, 2009, p. 25)", similar to elsewhere in the world.

   I also support the Shut Out report's suggestions regarding:

   - creating a complaints authority and compliance certification
   - increasing the number of, and funding for, advocacy services for people with disabilities in urban, regional and rural areas, and greater promotion of these services
   - enlisting advocates as intermediaries to ensure person-centred processes and models are effective and include measurement of appropriate outcomes (National People with Disabilities and Carer Council, 2009, p. 17).

   I also support the implementation gaps outlined in the University of NSW's review report, such as reforming PWD right's protection, especially access to free legal services and legal representation (Davy et al., 2019, pp. 22-23).

Furthermore, the Strategy should ensure that all States and Territories have made legislative changes under the commitments to the UN CRPD (Davy et al., 2019, p. 36). Additionally, coordination particularly between NDIS-related legislation and the Strategy should be undertaken to ensure a holistic approach and avoidance of legislative gaps.

b. **Disability-inclusion KPIs and benchmarking across all organisations** – Just as businesses must comply with the Trade Practices Act and report on their financial viability, the same should be applied to disability-related KPIs. All organisations, including businesses, not-for-profits and government organisations and their policies and programs must have enforceable, meaningful KPIs against which their viability is verified. These KPIs would reflect the UN review of Australia re: the CRPD.

c. Just as we are seeing increased demand for ESG (environmental, social and governance) compliance, e.g. the Dow Jones Sustainability Index, similar compliance should be applied to embedding disability-inclusion.

- Example 1: funding for rail or housing projects would be approved according to the extent to which the developer's organisations evidences disability-inclusive practices in their business and the transport project would also need to demonstrate how the project would align to the UN CRPD-related KPIs to support PWD's needs.

- Example 2: funding for new energy policy and programs (e.g. gas pipeline) would be approved according to evidence of how the new energy policy or program would support the UN CRPD-related KPIs and impact on PWD.

d. **Accountability/governance -** Increased regulation, monitoring and transparent reporting re: disability compliance and discrimination. Similar to my answer to 2a above.

e. **Decision-making -** Increased decision-making authority: 1) at least one PWD represented on all decision-making bodies, public sector, private sector, not-for-profit sector

f. **Enduring funding model -** I agree with the Shut Out 2009 report's statement that some submissions recommended that we "create a model of funding in which resources are available irrespective of changes to the economic climate or variability in political will (National People with Disabilities and Carer Council, 2009, p. 5)."

g. **Data collection -** To accurately reflect the PWD community, including people with 'invisible' or under-recognised illnesses, data collection must be improved. For example, ME/CFS is subsumed under 'other neurological conditions within the Australian Institute of Health and Welfare's Burden of Disease statistics. ME/CFS data should be collected as a distinct, separate category since current practices are resulting in the under-reporting and therefore systemic neglect of the estimated 250,000 Australian residents with ME/CFS. What doesn't get measured, doesn't get managed (let alone, improved).

Furthermore, I support gathering evidence through measurement and analysis for accountability and transparency as critical to inform the priorities. An example is the Fair Go report on disability inequality (Davy et al., 2019, p. 21).

h. **Complaints handling, enforcement and redress -** Sufficiently strong enforcement and redress regarding anti-discrimination laws, including the availability of affordable legal aid

and sufficiently resourced complaints handling systems, are needed. As noted by the Shut Out report, one important reason discrimination has become so systematic and entrenched is the lack of redress as well as the "remarkable lack of monitoring and enforcement of standards and no effective independent complaints process (National People with Disabilities and Carer Council, 2009, p. 16). "

My 2018 experience with the QLD Civil and Administrative Tribunal involved me having to strongly insist upon the availability of disability advocacy support during my hearing. I doubt that many PWD would have the will, capability or capacity to take a similarly strong stance to protect their human rights.

Furthermore, although the NDIS is heralded as "the best example of positive achievement under the [former] Strategy (Davy et al., 2019, p. 19)," I hold strong concern that apparently the NDIS' complaints handling system remains highly flawed, resulting in very few complaints being adequately addressed (Harris, 2020a).

i. **Rationale** - I am aware that among many decision-makers human rights is often a secondary concern compared to economic issues. Consequently, I think the enormous economic losses due to a) poor support for PWD needs and b) inadequate research funding to find appropriate treatments to reduce disability should be explicitly communicated to decision-makers [1].

Systemic change impacts

I hope that the above-mentioned systemic changes will lead to the following impacts:

a. **Social housing:** Social housing/affordable, disability-accessible housing availability must be increased to support the PWD population and to accommodate their poverty levels. In particular, social housing should be prioritised for people with severe or profound disability. As reported in a recent Melbourne University study of accessible housing, nearly 75% of over 1000 survey respondents indicated their current housing was not suitably accessible (Wiesel, 2020, p. 5).

In particular, I support the proposals outlined in the Shut Out report including:

• developing lower cost, higher empowerment supported accommodation models for people with an intellectual disability

• introducing accommodation and support services run by and for Aboriginal and Torres Strait Islander people with disabilities

• developing outcome-based key performance indicators and enforceable standards for all forms of accommodation as part of an accreditation process

• increasing the availability of public housing stock for people with disabilities (National People with Disabilities and Carer Council, 2009, p. 31).

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[1] For example, the National Centre for Neurological and Emerging Diseases' 2020 report found that the economic impact of ME/CFS in Australia is $14.5 billion/annum (Close et al., 2020). This almost the same as the $15 million economic impact of dementia in Australia in 2018 (Dementia Australia, 2020).

Safe, secure housing is a fundamental human right and according to homelessness services, once housing issues are appropriately addressed, most other problems and associated costs, including health, employment, domestic violence and other crimes, are significantly improved.

b. **Greater funding for health care for PWD, particularly early intervention and preventative health care:** this would include increased subsidies for essential medications as well as complimentary medicine. The unaffordability of healthcare often results in many PWD not accessing the care they need, resulting in the worsening of their health and increasing associated personal and community costs.

Furthermore, costs of early intervention and preventative health care should be subsidised to minimise long-term cost increases due to worsening health. Let us not wait until health levels reach severe, crisis levels before adequate health care is provided.

c. **Increase the DSP or reimburse via tax system** – the Disability Support Pension must be increased to meet the true costs of living among PWD. As stated in the Shut Out report, "the extraordinary gap between the level of income support and the cost of disability was seen as restricting the ability of people with disabilities both to live independently and to enjoy a decent standard of living (National People with Disabilities and Carer Council, 2009, p. 35)." Moreover, by being trapped in a severe poverty cycle, many PWD face worsening health, increasing costs and therefore a spiralling down of their quality of life, many to the point of suicide or other forms of early death.
A case in point is the systemic neglect of people with ME/CFS, most of whom are ineligible for the DSP and many receive no income at all (Emerge Australia, 2018). Unsurprisingly, many people with ME/CFS end up dying as much as 20 years younger from heart disease, cancer or suicide compared to the general population (Jason, Corradi, Gress, Williams, & Torres-Harding, 2006; McManimen et al., 2016).

Moreover, changes to the tax system could be made to entitle PWD to rebates or deductions for associated healthcare costs.

d. **Work** - Increased roles in part-time work for under 15 hours/week and workplace adjustments accommodate needs of PWD, such as room for assistive technology, conducive work environment (e.g. chemical-free, low noise, low lighting if person is light-sensitive, availability of on-site support staff).

Government can play a proactive role by 'leading from the front' and improve public service participation rates among PWD.

I support the suggestions listed in the Shut Out report, such as:

- setting employment targets in the public service at Commonwealth, state and territory and local government levels
- tracking students with disabilities after completion of school to determine how their funding and level of education translated to training and employment
- enabling students and graduates with disabilities to apply for equity-based programs that get people with disabilities into graduate jobs, akin to Indigenous cadetships
- immediately releasing 100–500 jobs to people with disabilities, through pilot programs, apprenticeships and training (National People with Disabilities and Carer Council, 2009, pp. 41-42).

e. **Education** – Improvements in support services for students with disabilities are essential as well as including disability awareness training among education staff and administrators. I support the additional proposals listed in the Shut Out report.

f. **Built environment and transport infrastructure standards** – all built environment, e.g. buildings, roads, public amenities, and transport infrastructure should include accessible design codes and standards. These codes and standards should be monitored for compliance and include penalties for non-compliance.

g. **Disability services:** I support the disability services workforce-related reforms suggested in the Shut Out report (National People with Disabilities and Carer Council, 2009, p. 24). These include:

- increased pay rates
- improved conditions
- improved education and training, particularly how to support PWD who face 'double disadvantage', e.g. Indigenous, CALD, LGBTQI, refugees, people in prisons or recent ex-prisoners.
- development of clear education and career pathways
- improved monitoring of workplace compliance with WH&S requirements.

3. What helps you to participate in the community, including to work or study?

- Quality, social connection → Validation/recognition from friends → boosts my self-esteem → enables me to make decisions with confidence about all aspects of my life. Note: many of my ME/CFS peers don't have this and therefore I've noticed that their health has not improved or worsened.
- Centrelink payments, e.g. DSP. Without this welfare income, I would end up homeless → worse health or even suicide risk.
- Safe, affordable housing – as I am stuck at home about 22 hours/day, this is essential to everything else (Wiesel, 2020).
- Reliable, affordable internet access (Geeks 2 U services)

4. What do you think could be done to help improve the attitudes of people in the community towards PWD?

See my answers to number 2 on pages 9 to 13.

a. What parts of your life do you think would improve the most if people in the community had better attitudes towards PWD?

All aspects of life, particularly the systemic impacts listed above in pages 12 and 13.

5. How can governments involve PWD in delivering the Strategy?

See my answer to item 2: include people as *meaningful decision-makers,* not just consulted, outside stakeholders, regarding the Strategy. Ideally, 20-25% of the staff managing and governing the Strategy should be PWD to reflect the population prevalence in Australia.

6. Should governments tell you more about what they are doing under the NDS and whether things are improving, or not, for people?

Yes. See my responses regarding 'Measuring Outcomes and Reporting, Point 5.1 in the Position Paper.' In their reporting, they need to demonstrate with clear, robust cause-and-effect evidence and data about how much things are improving.

7. Do you think organisations, businesses and governments work together well to create a more inclusive Australian society? How could this be improved?

No, I don't think they work well together, compared to what it should be, let alone in response to the UN review of Australia re: the CRPD. My opinion is based upon:

- the enormously horrific evidence from the Disability Royal Commission
- the fact that during COVID-19, it wasn't until April 2020 that the federal government even released a COVID-19 Disability Strategy and the fact that the DSP only received the two, once-off COVID-19 subsidies, which are still less than JobKeeper or JobSeeker.
- The fact that disability targets were omitted from the recent Closing the Gap targets re: Indigenous people.

However, compared to what it was like 5 or 10 years ago, I think it has improved, due to advocacy among PWD. My opinion is based upon:

- the fact that this NDS review is underway and that the UN has conducted a review of CRPD alignment
- better coverage in the media and research regarding disability, including previously ignored/invisible disabilities (e.g. dysautonomia, fibromyalgia, ME/CFS), including ABC's new journalist with a disability
- assistive technological improvements, e.g. telepresence robots
- amenities for PWD, e.g. invisible disability lanyards at Brisbane Airport (due to advocacy from autism community)
- more programs looking to include PWD (e.g. QLD Disability-Inclusive Disaster Risk Reduction program).

My recommendations for improvement are outlined in point XX.

a. Do you think governments are clear about what they do to support PWD?

Partially. Unfortunately, a lot of the information is too hard to understand, due to red tape jargon, lack of sufficient communications budgets and successive cuts to community services.

For example, the Disability Support Pension and NDIS application forms are too complex, the government has had to roll-out programs to assist PWD to understand these flagship programs.

Isolated PWD - Another of my concerns is whether the most isolated, non-connected PWD (e.g. homeless people, people in prisons, housebound/bedbound people) are accessing disability-related information.

Low literacy - Moreover, I'm not convinced that people with low or nil literacy, including PWD with low/nil literacy, are being sufficiently reached. Apparently 15% of the Australian native-English-speaking general population has low or no literacy and numeracy (Kelly, 2020b).

b. Are there organisations other than governments and disability organisations that you think could be more involved in helping to improve the lives of PWD?

I think that the business sector and trade unions could help by agreeing to embed and abide by ESG (environmental, social and governance) compliance, similar to how they are integral to agreeing to embedding environmentally-friendly practices. Without the private sector and unions, progress is likely to be limited.

Therefore, I recommend the following organisations - particularly start with the ones that already demonstrate a commitment (even if it's limited) to ESG, especially human rights.

- Australian Institute of Company Directors
- Australian Industry Group
- Chambers of Commerce
- Industry councils
- Trade unions
- Superannuation industry

To encourage business support for the Strategy, I think it's useful to engage with and build alliances with other orgs that have already been working on embedding greater equity for minorities, e.g. racial, gender, sexual orientation, Indigenous, etc; as I think they face similar challenges in improving equity.

To encourage business sector and union cooperation, I think it is useful to emphasise both human rights and economic benefits as key rationales.

Post-script

Rationale/drivers

I appreciate that the Strategy, like many other strategies, often provide the blueprint for 'what' and 'how' changes are to be done. However, without a clear, widespread understanding of the 'why', the rationale, a strategy's chances of progress remain limited. Consequently, below I have outlined three key drivers:

UN CRPD commitment and leadership

Australia was one of the first countries to ratify the UN CRPD. Our nation has a chance to demonstrate real, international leadership in an area of increasing growth by developing a solid Strategy that genuinely addresses the needs of PWD.

Increased demand and economic imperatives

As the Australian population ages and climate change worsens people's health, including climate change refugees who want to seek asylum here, the disability population will grow. Consequently, the human and economic cost-imperative and therefore demands to address the UN CRPD in Australia will likely grow too.

Civil society

As stated by the Shut Out report, "the national ideal of a 'fair go' is still only imperfectly extended to people with disabilities. We want our NDS to tackle that disadvantage (National People with Disabilities and Carer Council, 2009, p. iv)." Civil society is often measured according to how well a society treats its most vulnerable. Therefore, if Australia aspires to becoming an even better, stronger civil society, then the Strategy must be robust and comprehensive to ensure that PWD, as highly vulnerable members of Australian society, are able to have the same opportunities as others, to live and be treated with dignity and to realise their life's fullest potential. As our own national anthem states, "with courage let us all combine to Advance Australia Fair."

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