



Post-Polio Victoria Inc.

Submission on the National Disability Strategy

4 November, 2020



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

Via email: disabilityreform@dss.gov.au

Dear National Disability Strategy Governance and Engagement Section,

Post-Polio Victoria Inc thanks the Department of Social Services for the opportunity to give our input to the next iteration of the *National Disability Strategy*.

We support the socio-ecological, lifeworld-led model of healthcare, which takes enablement of polio survivors, our families, social networks, our physical and mental health professionals - and even our architects and builders - as our basic principles.

We would be pleased to elaborate further upon the issues we have raised in this submission if that would be considered useful.

In acknowledgement of the specific - and complex - challenges and needs of the First Nations peoples of Australia, Post-Polio Victoria Inc respectfully requests that special consideration be given by the Department of Social Services to comprehensive and equitable protection of their disability human rights.

About Post-Polio Victoria (Inc)

Post-Polio Victoria Inc (PPV) is a non-profit organisation that is run by a volunteer management committee consisting largely of people who have polio.

PPV is committed to:

- assisting people with polio to stay connected to their community;
- advocating for post-polio needs to health professionals, services and government authorities; and
- providing information, advice and raising awareness of issues that surround polio to healthcare providers and the broader community.

Post-Polio Victoria Inc.

Submission on the National Disability Strategy, 4 Nov, 2020

© Barbary Clarke – PPV Policy Working Group

Executive Summary

Issues which need to be urgently addressed by the *National Disability Strategy*:

- Coordination of efforts by Federal, State, and Local Governments, healthcare organisations, agencies, and disability advocacy groups to address measurable action targets/ outcomes set in the *National Disability Strategy*;
- Structural legislative discrimination against polio survivors over 65 through their exclusion from the NDIS;
- Structural discrimination inherent in the failure of the Australian Government to mandate appropriate levels of accessibility being built into all new dwellings via the *National Construction Code*;
- We oppose the proposed tendering-out of *National Disability Insurance Scheme (NDIS)* government-appointed disability assessment to corporate organisations;
- Timely, complete and verifiable reporting of progress in achieving:
 - a) universal accessible housing design in Australia;
 - b) the objectives of the *National Disability Strategy*;
 - c) the operation of the *National Disability Insurance Scheme (NDIS)*

by the Department of Social Services in conjunction with the Federal Attorney-General's Department to the *UN Committee on the Rights of Persons with Disabilities*.

Polio Survivors, Trauma, and the Late Effects of Polio/Post-Polio Syndrome

A number of our polio survivor members have experienced medical trauma (Hall & Hall, 2016) and/or psychological neglect (Wilson, 2008) due to past, and present, disability assessments and treatment based on a medical model.

They have been subjected to multilevel stigma (Cook, Purdie-Vaughns et al, 2014; Hatzenbuehler & Link, 2014) at structural, interpersonal, and individually-internalised levels which have interacted to detrimentally affect their ability to seek assistance, health outcomes and financial situations.

All polio survivors have had to be tough and resilient.

Survivors of Polio Myelitis, or “Infantile Paralysis”, are often wrongly excluded from the NDIS because politicians, bureaucrats and health professionals fail to understand the bi-modal incidence of the disease, in which motor neurons are destroyed (leading to paralysis), but sometimes grow back in an attenuated and shorter-lived form which result in re-emergence, or Late Effects of Polio (Post-Polio Syndrome), often around 40 years after initial infection. The resulting muscle fatigue, and other debilitating symptoms, are deemed to be the result of ageing, instead of actually a direct result of the original infantile disease (Duncan et al, 2018; Groce et al., 2014).

Recommendations to Address Multilevel Discrimination Against People Living With Polio

- 1) Adopt a human rights-based model of care for all polio survivors re the *National Disability Insurance Scheme (NDIS)* (consistent with Principle 5(d) and Recommendation 6(e) of the *Concluding Observations of the UN Committee on the Rights of Persons with Disabilities, 2019*).
- 2) Ensure equal opportunities for all minority, and disadvantaged, groups to access the *NDIS* (consistent with Principle 5(e) of the *Concluding Observations of the UN Committee on the Rights of Persons with Disabilities, 2019*).
- 3) Excise *Age Discrimination Act 2004*, s 41(1)(fba), which the Commonwealth Senate has already admitted to be discriminatory against people over 65 years old, who are excluded from the *NDIS*, and which contradicts Article 5 of the *UN Convention on the Rights of Persons with Disabilities* to counteract existing neglect, exploitation and abuse of this segment of the disability community.
- 4) Support polio survivors over 65 years old by including them in the *NDIS* (consistent with Recommendation 6(e) of the *Concluding Observations of the UN Committee on the Rights of Persons with Disabilities, 2019*).
- 5) Mandate Gold Level, with some Platinum Level features (Livable Housing Australia, 2017:19) minimum accessibility standards (such as flooring materials and wheelchair turning circle space in bedrooms), for 100% of new, and substantially modified, Australian dwellings by 2030 in the *National Construction Code*.

Post-Polio Victoria Inc.

Submission on the National Disability Strategy, 4 Nov, 2020

© Barbary Clarke – PPV Policy Working Group

- 6) Establish and fully fund a regulatory body, independent of both government and the building industry, which assists the Attorney-General's Department with timely reporting to the *UN Committee on the Rights of Persons with Disabilities* to monitor attainment of stringent interim deadlines regarding percentages of new dwellings that include mandatory minimum accessibility standards.
- 7) De-mystify the operation of the *NDIS*, the *National Disability Strategy* and the *National Disability Agreement* through provision, and publication, of:
 - a) Credible and reliable quantitative and qualitative evidence in a national and state data set (consistent with point 4(i) of the *Concluding Observations of the UN Committee on the Rights of Persons with Disabilities, 2019*)
 - b) National marketing and awareness-raising campaign about the above evidence and all the parts of the disability system and how they work together, including reporting mechanisms.
- 8) Retain the Vision, Guiding Principles and Outcome Areas outlined in the 2010-2020 version of the *National Disability Strategy* (Department of Social Services, July, 2020)
- 9) Set concrete, rather than "aspirational", measurable targets. undertakings and outcomes in the *National Disability Strategy 2020-2030*. The problem with "aspirational" targets was amply illustrated by only 5% of COAG's "aspirational goal" of 100% accessible housing by 2020, enshrined in the *National Disability Strategy 2010-2020*, was achieved. This signified deficiencies in Intra-government and broader community collaboration.
- 10) A mechanism, such as an umbrella Office of National Disability Strategy, be established to ensure accountability of those undertaking to achieve defined and measurable targets must be included for each outcome area. Allegedly a tardy, evasive, and misleading report was made by the Australian Government to the *UN Committee in the Rights of Persons with Disability* regarding progress towards the housing accessibility goal. The NGOs' *Shadow Report* to the *UN Committee* (Australian Civil Society CRPD Shadow Report Working Group, July 2019) drew its attention to lack of progress towards accessible housing. In 2017 the *UN Committee* pointedly requested comprehensive evidence of progress by the Australian Government, prior to making its *Concluding Observations* on Australia in 2019. In 2019 the *UN Committee* noted "The significant proportion of the existing built environment that is inaccessible and the lack of mandated national access requirements for housing in the *National Construction Code*" & recommended that the Government "Amend the federal law by including mandatory rules on access for all new and extensively modified housing" (*UN Committee on the Rights of Persons with Disabilities, 15 Oct, 2019*).
- 11) People with disability and their advocacy organisations must be involved in the monitoring and reporting process (Davy et al, 2019). Adequate funding must be provided to independent disability Non-Government Organisations (NGOs) to write *Civil Society's Shadow Reports* to the *UN Committee on the Rights of Persons with Disability*, to *Universal Periodic Reviews*, to the *Sustainable Development Goals (SDGs)*; and to the *Commission on the Status of Women*.

Post-Polio Victoria Inc.

Submission on the National Disability Strategy, 4 Nov, 2020

© Barbary Clarke – PPV Policy Working Group

- 12) Set up an easily-accessible national complaints mechanism for people with disability who have been subject to discrimination, violence, abuse, exploitation and neglect in all settings, including all those not eligible for the National Disability Insurance Scheme and, particularly, older women with disabilities

Conclusion

Post-Polio Victoria Inc thanks the National Disability Strategy Governance and Engagement Section again for being able to represent the polio-specific views of our members.

References

- Australian Civil Society CRPD Shadow Report Working Group. (July 2019). *Australian Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities: UN CRPD Review 2019*. Australia: Compiled by Australian Disabled People's Organisations (DPOs), Disability Representative Organisations (DROs) and Disability Advocacy Organisations. Available at: <https://dpoa.org.au/wp-content/uploads/2019/08/CRPD-Shadow-Report-2019-English-PDF.pdf>
- Australian Network on Universal Housing Design (ANUHD). (14 Nov, 2018). *Australian Network on Universal Housing Design - Response to the Australian Building Codes Board's Accessible Housing Options Paper*. Queensland: ANUHD.
- Cook, J.E., Purdie-Vaughns, V., Meyer, I.H., & Busch, J.A.T. (2014). Intervening within and across levels: A multilevel approach to stigma and public health. *Social Science and Medicine*, 103:101-109.
- Department of Social Services. (July 2020). *National Disability Strategy – Position paper*. Canberra: Australian Government.
- Davy, L., Fisher, K., Wehbe, A., Purcal, C., Robinson, S., Kayess, R. & Santos, D. (2019). *Review of implementation of the National Disability Strategy 2010-2020: Final report*, UNSW Social Policy Research Centre, Sydney. Available at <http://dx.doi.org/10.26190/5c7494b61edc4>
- Duncan, A., & Batliwalla, Z. (2018). Growing Older with Post-Polio Syndrome: Social and Quality-of-Life Implications. *SAGE Open Medicine*. 6:1-7.
- Groce, N.E., Banks, L.M., & Stein, L.M. (2014). Surviving Polio in a Post-Polio World. *Social Science and Medicine*. 107:171-178.
- Hall, M.F., & Hall, S.E. (2016). *Managing the Psychological Impact of Medical Trauma: A Guide for Mental Health and Health Care Professionals*. New York: Springer Publishing Co.
- Hatzenbuehler, M.L., & Link, B.G. (2014). Introduction to the Special Issue on Structural Stigma and Health, *Social Science and Medicine*, 103:1-6 <https://doi.org/10.164>
- Livable Housing Australia, *Livable Housing Design Guidelines*, 4th edition, 2017.

Post-Polio Victoria Inc.

Submission on the National Disability Strategy, 4 Nov, 2020

© Barbary Clarke – PPV Policy Working Group

UN Committee on the Rights of Persons with Disabilities. (15 Oct, 2019). *Convention on the Rights of Persons with Disabilities - Concluding observations on the combined second and third periodic reports of Australia*. Geneva: United Nations.

Wiesel, I. (31 Aug 2020). *Lived Experience and Social, Health and Economic Impacts of Inaccessible Housing – Report submitted to the Australian Building Codes Board RIS*. Melbourne: Melbourne Disability Institute, University of Melbourne and the Summer Foundation. Available at:

Wilson, D.J. (2008). Psychological Trauma and its Treatment in the Polio Epidemics. *Bulletin of the History of Medicine*, 82(4):848-877