

Submission to the **National Disability Advocacy Framework 2022-2025**

By **Christine Regan**

Introduction

I make this submission as a private citizen because I am passionate that disability advocacy must be maintained, improved and extended.

I was unable to provide this submission before the closing date due to significant personal illness and challenging family circumstances. I respectfully request that it be accepted as part of the consultation. I am happy to be contacted if clarification or further information is required.

My experience in disability began when I was raised with a sister with disability and then became the mother of my daughter with Down syndrome. My roles in disability have included initiator board member in several local, regional and national disability organisations, non-government disability advocate and development officer, Statutory Board member at the NSW Anti-Discrimination Board (2009-2012), member of various NSW Ministerial Advisory and Reference committees relating to disability, member State Electoral Commission disability advisory committee, convenor of the NSW Disability Network Forum (for peak disability advocacy representatives) and the NSW Aboriginal Gathering (for older people and people with disability), Complaints Officer and also Disability Rights trainer at the NSW Ombudsman. I joined the NDIS Quality and Safeguards Commission when it commenced in July 2018, where I worked as the first State Director for NSW and ACT, and then as the initial Principal Engagement Advisor in the National Office.

I have recently retired and am now looking to future roles to support people with disability.

Comments on draft National Disability Advocacy Framework 2022-2025

I generally agree with the intentions and content of the Framework. However, I suggest:

1. Including people with disability who have simultaneous issues with several intersecting agencies and services, e.g. health and insecure housing, inadequate income and escalating needs, etc.
2. Under the **Participation and Inclusion** Principle: *Disability advocacy is an essential tool for fostering the full and effective participation and inclusion of people with disability in society.* Unlike other principles, the wording here is passive and stationary. I suggest: Disability advocacy will work to foster the full and effective participation and inclusion of people with disability in society and in the services and systems that affect them.
3. Under the **Safeguards** Principle: *The rights of people with disability are promoted, upheld and protected, and people with disability feel safe and enjoy equality before the law.*

This Principle must include more than equality before the law, but must also include equality as for other people within systems. This is because sometimes the “letter of the law” by its very nature can serve to exclude people with disability until practices and legislation are modernised and updated.

4. Under **Outcomes**: I am very supportive of the Outcome: *People with disability have a range of ways to express their views and wishes about supports and services, play an active role in working out how things will improve, and can access a complaints mechanism and independent support and advice when providing feedback or making a complaint in relation to the supports and services they purchase or engage*. It is important that people with disability are not unfairly excluded at the front door, so this laudable outcome should also include more than just the “supports and services” they “purchase or engage”, but also access to important or preferred past-times, consultations, and activities in which other people in Australia can participate or initiate.
5. As a mother and sister, I believe that families and significant others should be included in supporting the advocacy of people with disability. However, this should be with the express consent of the person with disability or on their behalf with their nominated personal representative depending on capacity. Further, the privacy of decision-making of the person with disability should be identified and respected at all times, and this must also contain reasonable consents. However, this should not limit appropriate and available outcomes for the person. A statement in an addendum or similar should be made about the inclusion of others as part of the advocacy process.
6. The Framework describes **Individual advocacy** *a one-on-one approach, undertaken by a professional advocate, relative, friend or volunteer, to prevent or address instances of unfair treatment or abuse*. The Framework must identify that individual advocacy **MUST** be independent of the services and supports used by a person with disability. There is no doubt that support services often appropriately undertake aspects of advocacy in their provision of those supports and services. However, in my advocacy and regulatory roles, I saw too many instances where a support service provided individual advocacy to a person with disability, and this individual advocacy necessarily limited the actions and outcomes available to the person and/or undertaken by the support service. This habitually and routinely happened even where support services said they separated the management and provision of advocacy from their direct services. This constitutes an obvious and regular conflict of interest, despite often being well meant, and must be disallowed. All individual advocacy must be totally independent.
7. Further, individual advocacy undertaken by advocacy agencies must be provided by advocates with appropriate experience and regularly updated training, involving contemporary regulation and legislation, as well as using person-centred approaches, providing non-judgemental advocacy supports and understanding personal/professional boundaries.
8. The Framework defines systemic advocacy as: **Systemic advocacy** *involves working for long-term social change to ensure the collective rights and interests of people with disability are served through legislation, policies and practices*. It is critically important to recognise that systemic advocacy is necessary to

- a. Avoid resolving the same problem/issue for a person with disability over and over again for different people.
 - b. Eliminate the distress of people with disability who experience issue/problems that others before them have already endured.
 - c. Save previous money and time expended on resolving the same or similar issues repeatedly.
 - d. Use a person-centred and outcomes approach to improve systems and systemic responses, policy and legislation.
 - e. Enable multi-system approaches, interactions and responses towards improvements for individuals and groups, and to advance the rights of people with disability.
9. The Framework should require all regulatory agencies to clearly spell out and mandate the expected role of agencies and services used by people with disability to enable, assist and respond to disability advocacy.
10. Importance of access to disability advocacy:
- a. Governments and disability advocacy must work towards prohibiting services and agencies from disallowing people with disability to access the disability advocacy they require. In my experience in disability regulation, I saw unnecessary and often deliberate impediments imposed on people with disability when they sought to make complaints, raise issues or access disability advocacy.
 - b. Disability advocacy can also work to assist people with disability to understand their rights and to develop equitable and appropriate expectations about the exercise of their rights.
 - c. Disability advocacy should be actively and regularly promoted to people with disability, their families and supporters, to the agencies and services they use or want, and to other regulatory authorities.
 - d. Access to disability advocacy must not be specifically limited to people with disability who are NDIS participants or who use disability supports and services. This should be clearly and repeatedly identified within the Framework. People with disability who use the NDIS might require advocacy assistance with the NDIS, or with other aspects of their lives. Similarly and importantly, most people with disability do not use the NDIS and might require critical assistance to exercise of their rights and entitlements, and to simply enable lives reflective of others in the community.
 - e. Disability advocacy providers should be funded to educate disability services and others about how to respond to the issues of people with disability, especially to continuously improving the knowledge, understanding, intentions and actions of those services.
11. Implementation and Reporting:
- a. In order to make National Disability Advocacy Framework effective, the DSS should develop and publish an Implementation Plan for the Framework that:
 - i. Establishes agreements with other Commonwealth agencies and State and Territory Governments, about the implementation of the Framework and to provide regular reports against implementation.
 - ii. Identifies measurable indicators of progress/achievement for each principle, objective and outcome.

- iii. Tracks the progress of achievement (or otherwise) against each, using the indicators
- iv. Regularly reports on progress and publishes those reports
- v. Evaluates the overall achievement, prior to developing the Framework for the next term.
- vi. Publishes the evaluation report.

12. Operation of the Framework:

- a. Disability Advocacy is differently funded across all levels of government and jurisdictions. In order to provide appropriate local access of local or nearby advocacy to people with disability, the Framework must work towards **formal agreements** between levels of government and with states and territories about:
 - i. **Adequate funding** that responds to advocacy demand of people with disability where they live, their linguistic and cultural requirements, their personal circumstances etc.
 - ii. **Relative roles and functions** or *who will do what* in providing adequate and comprehensive individual, systemic and self/peer advocacy to people with disability; thereby reducing gaps and buck-passing in responding to the advocacy needs of people with disability.
 - iii. Clarification about the interaction and/or intersection of the National Disability Framework with other and mainstream regulatory authorities. In other words, how will regulatory authorities work with the National Disability Advocacy Framework.

In Conclusion

I am happy to be contacted if clarification or further information is required.

As I was unable to provide this submission before closing date due to significant personal illness and challenging family circumstances, I respectfully request that it be accepted as part of the consultation.

I look forward to your acknowledgement of receipt of this submission.

Thank you for your understanding and consideration.

Kind regards,



Christine Regan

