Faculty of Medicine, The Department of Developmental Disability Neuropsychiatry 3DN

Response to the National Disability Strategy Position Paper

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Summary of Response

- The inclusion of Health and Wellbeing in the National Disability Strategy is critical as people with intellectual disability face stark health inequalities and die prematurely often from potentially avoidable causes (1).
- Given the very high rates of mental health concerns for people with intellectual disability and autistic people, we suggest that recommendations relevant to the revision of the National Disability Strategy from our National Round Table Communique be represented in the new Strategy. The Communique can be found here https://www.3dn.unsw.edu.au/education-resources/health-mental-health-professionals/2018-national-roundtable-communique
- We strongly support the new features to enhance accountability and to improve the implementation of the Strategy.
- It is critical that the voice of people with lived experience of disability continues to drive the content of the Strategy and subsequently its implementation and evaluation.

About the Department of Developmental Disability Neuropsychiatry

The Department of Developmental Disability Neuropsychiatry (3DN) at UNSW Sydney leads National and State developments in Intellectual and Developmental Disability Mental Health through education and training of health and disability professionals and by conducting research with a particular focus on the health and wellbeing of people with intellectual and developmental disabilities. 3DN's vision is to work with people with intellectual and developmental disabilities, their carers and families, to achieve the highest attainable standard of mental health and wellbeing. 3DN is led by UNSW's inaugural Chair of Intellectual Disability Mental Health, Professor Julian Trollor, who has over 20 years of clinical experience in the management of people with ID and complex health and mental health problems. He and his staff have extensive experience with a range of disability service providers and professionals, and have led or contributed to numerous legislative, policy and service reviews in the disability arena. More information about 3DN and the Chair IDMH can be found on our website: http://3dn.unsw.edu.au/

Below is our response to each of the questions asked in the Position Paper.

Response to Question 1:

- Yes, we agree with the six key outcome areas for the Strategy.
- The health and wellbeing outcome area is of particular importance because people with intellectual disability experience poor health outcomes compared to the general population. This issue featured prominently in the recent Health hearings of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (https://disability.royalcommission.gov.au/public-hearings/public-hearing-4).
- We look forward to seeing the content described within the health and wellbeing outcome area. In particular, that it covers all areas of health (physical and mental health), from health promotion, preventative health, health care, and palliative care.
- A key consideration for this new iteration of the Strategy is to articulate how these outcome areas are interconnected and influence one another.

Response to Question 2:

- The guiding principle of 'involve and engage' is essential, however, we suggest that the language is revised because listening to people doesn't necessarily lead to including their views in policy and programs.
- We also suggest that the guiding principle of co-design be included, to ensure that policy and programs are being driven by people with lived experience of disability.

Response to Question 3:

- We support a stronger emphasis on improving community attitudes across all outcome areas.
- Attitudes toward the health needs of people with intellectual disability still presents as a barrier to accessing physical and mental healthcare (2-5).

Response to Question 4:

- We support the articulation of the roles and responsibilities of various levels of government.
- The articulation of role and responsibilities is important in the realisation of the right to health, as siloing continues to be a problem between disability and health services, and there is a lack of clarity on respective roles and responsibilities (6).
- A particular focus should be given to areas where there is contention over who is responsible, for example the area of behaviours of concern.
- The Strategy may benefit from including guidance on how to work collaboratively in areas of joint roles and responsibilities, particularly when supporting people with multiple disadvantage.

Response to Question 5:

- The non-government sector has an essential role in improving health outcomes for people with disability.
- Within the health sphere it would be important to articulate the role that the private health care system plays in meeting the health needs of people with disability.

Response to Question 6:

- The kinds of information that should be made available to the public include, process, intermediate and long-term evaluation data within each of the key outcome areas.
- If the Strategy includes targeted action plans and engagement plans it would be important to report on the implementation and achievements of these plans.
- Annual reporting should not focus only on the commitments of government but the action that they are taking to achieve the outcomes of the Strategy. This will allow insights into the commitments that have and have not been implemented.
- The availability of process evaluation data is critical as there is still much to learn about implementing policy and programs that meet the needs of people with disability. The availability of process data may also provide insights into how the guiding principles of the Strategy have been applied to achieve the desired outcomes.
- Within the health domain we suggest reporting against the World Health Organisations six core components of the healthcare system including: i) service delivery, ii) health workforce, iii) health information systems, iv) access to essential medicines, v) financing, and vi) leadership and governance (7).

Response to Question 7:

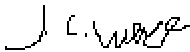
- We support an action-oriented approach to implementation.
- It would be essential that people with lived experience drive the focus and content of these action plans, including the process of prioritising deliverables.

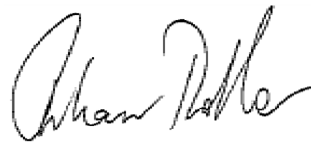
Response to Question 8:

- We strongly support the inclusion of people with disability in the delivery and monitoring of the next Strategy.
- To minimise the number of resources related to the strategy we suggest that the content in the proposed engagement plan be included in the implementation plan of the Strategy, so that its content is not forgotten.

Thank you for the opportunity to respond to the National Disability Strategy Position Paper. Should you wish to discuss the content of this submission please do not hesitate to contact us (j.weise@unsw.edu.au or j.trollor@unsw.edu.au).

Sincerely,





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References

1. Trollor J, Srasuebkul P, Xu H, Howlett S. Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. BMJ Open. 2017;7(2).
2. Bonell S, Ali A, Hall I, Chinn D, Patkas I. People with Intellectual Disabilities in Out-of-Area Specialist Hospitals: What Do Families Think? Journal of Applied Research in Intellectual Disabilities. 2011;24(5):389-97.
3. Longo S, Scior K. In-patient psychiatric care for individuals with intellectual disabilities: the service users' and carers' perspectives. Journal of Mental Health. 2004;13(2):211-21.
4. Lennox N, Chaplin R. The psychiatric care of people with intellectual disabilities: the perceptions of trainee psychiatrists and psychiatric medical officers. Australian and New Zealand Journal of Psychiatry. 1995;29(4):632-7.
5. Lennox N, Chaplin R. The psychiatric care of people with intellectual disabilities: the perceptions of consultant psychiatrists in Victoria. Australian and New Zealand Journal of Psychiatry. 1996;30(6):774-80.
6. Weise J, Fisher KR, Turner B, Trollor JN. What is the capability of the Australian mental health workforce to meet the needs of people with an intellectual disability and co-occurring mental ill health? Journal of Intellectual & Developmental Disability. 2020;45(2):184-93.
7. WHO. Everybody's business--strengthening health systems to improve health outcomes: WHO's framework for action. 2007.