New South Wales

Special Commission of Inquiry into Healthcare Funding

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Submission to the Special Commission of Inquiry into Healthcare Funding

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Introduction

Our submission focuses on the healthcare needs of people with intellectual disability in NSW. Approximately 160,000 people in NSW have intellectual disability. Close to 460,000 more would be considered to have "Borderline" intellectual disability – people in this group often have unrecognised support needs.

Attention to the funding of health care for people with intellectual disability is warranted because compared with the general population, people with intellectual disability have much higher rates of physical and mental health conditions, but experience substantial barriers to health care. Recommendations relating to health care for people with cognitive disability were highlighted in Volume 6 of the Final Report of the Disability Royal Commission.

High rates of medical conditions, including those of a complex nature, means that as a group, people with intellectual disability access services across all levels of the public health system. High rates of low income status in this group means many are entirely reliant on public health services. People with disabilities are identified as a priority group with the NSW Health Future Health Report. The barriers to care that they experience are therefore a good exemplar of the ways that public health systems could be improved to ensure more equitable health care for all.

Below we give a brief background to our organisation, before addressing specific Terms of Reference of the Inquiry.

About NSW CID

The NSW Council for Intellectual Disability (CID) is a systemic advocacy organisation that works to ensure all people with intellectual disability are valued members of the community. CID has been a leader in disability rights for more than 60 years.

People with disability are at the front and centre of everything we do – they are decision makers, staff members, board members and spokespeople. We work to build a community that protects rights, includes everyone and supports people well. We focus on issues that people with disability tell us are important, such as the NDIS, health, jobs, education, transport and safety.

CID promotes human rights. We help people with disability to be heard, we speak up on the big issues and campaign for change. We advise on how to be more inclusive so that our society is equal and accessible.

CID acknowledges the valuable input of Professor Julian Trollor in preparing this submission. Professor Trollor is Head of Department of Developmental Disability (3DN), UNSW Medicine and Health and Director of the newly established National Centre of Excellence in Intellectual Disability Health. This is a major initiative supported by the Australian Government, Department of Health and Aged Care and has been funded as part of the National Roadmap to Improve the Health of People with Intellectual Disability. The Consortium is led by UNSW Sydney. CID is one of 8 other consortium members. Establishing Centre is a vital step in improving the health of people with intellectual disability.

Response to Terms of Reference

A. The funding of health services provided in NSW and how the funding can most effectively support the safe delivery of high quality, timely, equitable and accessible patient-centred care and health services to the people of NSW, now and into the future

Research has consistently shown that people with intellectual disability do not experience equitable health care and health outcomes. Australian research has shown people with intellectual disability experience numerous barriers accessing appropriate health care in a range of settings, including General practice[1], Mental Health[2], and End-of-Life Care[3], as a few examples.

Research conducted by 3DN indicates that outcomes for people with intellectual disability in NSW are very poor, with mortality rates being 2-3 times higher[4], and preventable deaths occurring at a rate more than double the general population, and accounting for 38% of all deaths[5].

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[1] Shea, B., Bailie, J., Dykgraaf, S. H., Fortune, N., Lennox, N., & Bailie, R. (2022). Access to general practice for people with intellectual disability in Australia: a systematic scoping review. *BMC Primary Care*, *23*(1), 1-11.
[2] Whittle, E. L., Fisher, K. R., Reppermund, S., Lenroot, R., & Trollor, J. (2018). Barriers and enablers to accessing mental health services for people with intellectual disability: a scoping review. *Journal of Mental Health Research in Intellectual Disabilities*, *11*(1), 69-102.
[3] Wark, S., Hussain, R., Müller, A., Ryan, P., & Parmenter, T. (2017). Challenges in providing end-of-life care for people with intellectual disability: Health services access. *Journal of applied research in intellectual disabilities : JARID*, *30*(6), 1151–1159. https://doi.org/10.1111/jar.12408
[4] Florio, T., & Trollor, J. (2015). Mortality among a cohort of persons with an intellectual disability in New South Wales, Australia. *Journal of Applied Research in Intellectual Disabilities*, *28*(5), 383-393.
[5] Trollor, J., Srasuebkul, P., Xu, H., & Howlett, S. (2017). Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ open*, *7*(2), e013489.

People with intellectual disability have very high health needs, and access NSW Health services (inpatient stays, emergency departments and outpatient mental health services) at rates more than double the general population, at more than twice the costs[6,7].

However, it is important to note that much of this cost could be prevented: compared with the general population, people with intellectual disability in NSW are between 3.5 and 4.5 times more likely to experience potentially preventable hospitalisations[8], demonstrating the individual and financial benefits of addressing their health care needs more effectively.

Epilepsy provides a good example of the costs of poorly integrated health care. About 22% of people with intellectual disability have epilepsy, and hospital presentations for epilepsy are high in this group. Half of people with intellectual disability who present to a NSW hospital with acute epilepsy will present again within a year. Yet, improved treatment pathways, adherence and managing comorbid physical or mental health conditions could address the risk of re-admission[9].

B. The existing governance and accountability structure of NSW Health, including:

ii. the engagement and involvement of local communities in health service development and delivery

Consulting with specific groups, such as people with intellectual disability, and their supporters, is an essential step to identifying cost-effective ways to improve health care. This should include identifying *reasonable adjustments:* that is*,* changes which remove a barrier that would otherwise prevent a person with disability accessing equitable services.

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[6] Trollor, J., Reeve, R., & Srasuebkul, P. (2016). Utilisation and costs of hospital services for patients with intellectual disabilities. *Journal of Intellectual Disability Research*, *60*(7-8), 75

[7] Srasuebkul, P., Cvejic, R., Heintze, T., Reppermund, S., & Trollor, J. N. (2021). Public mental health service use by people with intellectual disability in New South Wales and its costs. *Medical Journal of Australia*, *215*(7), 325-331.

[2] Weise, J. C., Srasuebkul, P., & Trollor, J. N. (2021). Potentially preventable hospitalisations of people with intellectual disability in New South Wales. *Medical Journal of Australia*, *215*(1), 31-36.

[9] Liao, P., Vajdic, C. M., Reppermund, S., Cvejic, R. C., Watkins, T. R., Srasuebkul, P., & Trollor, J. (2022). Readmission and emergency department presentation after hospitalisation for epilepsy in people with intellectual disability: a data linkage study. *PloS one*, *17*(8), e0272439.

Recommendation 6.32 from The Final Report of the Disability Royal Commission stated:

> *The Australian Government and state and territory governments, in consultation with people with disability, should:*
>
> *a. identify and publish a list of frequently needed adaptations and supports (including communication supports) to enable people with disability to receive high-quality health care in all publicly funded settings. Adaptations and supports may need to be tailored to individual needs and additional supports may be required. These should include:*
>
> - *environmental modifications and aids to reduce sensory loads, such as dimmer lighting, reduced background noise and noise-cancelling headphones*
> - *preparatory action to familiarise the person with disability with clinical environments, such as hospital tours and animated videos*
> - *different modes of service delivery, such as home visits, and taking a forward-looking approach to minimise distress associated with certain procedures – for instance, taking extra blood to reduce the need for additional blood draws, or undertaking multiple procedures at once if sedation is required to decrease the number of hospital visits*
> - *novel and flexible approaches to pre-medication, including sedation, to reduce distress and anxiety before critical medical procedures.*
>
> *b. review hospital (admitted and non-admitted care) and primary health care funding models to ensure these adaptations and supports can be implemented in all relevant settings.*
>
> *c. disseminate information about the provision of adaptations and supports in a range of accessible formats.*
>
> *Final Report of the Disability Royal Commission*, Volume 6, Chapter 4, pp. 391-2.

Consultation with people with disability, including intellectual disability, is therefore warranted.

C. The way NSW Health funds health services delivered in public hospitals and community settings, and the extent to which this allocation of resources supports or obstructs access to preventative and community health initiatives and overall optimal health outcomes for all people across NSW.

Most people with intellectual disability should be able to access their primary and preventative care locally through ordinary GPs, with reasonable adjustments as needed.

However, some people with complex care needs, high anxiety, or past medical trauma may need more adjustment than can be provided in a GP's office. These people benefit from accessing specialised services. The establishment of the Specialised Intellectual Disability Health teams was a welcome breakthrough for those with unmet health needs who now can receive a review by a clinician with experience working with people with intellectual disability. Recommendation 6.33 of the Final Report of the Disability Royal Commission, on provision and evaluation of specialised health and mental health services at local, statewide, and national levels[10].

An evaluation of the existing teams was planned but we understand it has been delayed. So it is not yet possible to fully understand their impact.

However, based on anecdotal reports, CID would support an expansion of the number and scope of these teams and their scope so that they can provide preventative medicine for those who need additional adjustments to care, in a setting that allows a gradation of reasonable adjustments.

F. The current capacity and capability of the NSW Health workforce to meet the current needs of patients and staff, and its sustainability to meet future demands and deliver efficient, equitable and effective health services, including:

i. the distribution of health workers in NSW;

Reports we have heard regarding access to care would suggest there is a shortage of clinicians with expertise in intellectual disability health in country areas, and most particularly regarding intellectual disability mental health.

ii. an examination of existing skills shortages;

Objective 4 of the Future Health Strategic Framework 2022-2032 says that *"Staff are supported to deliver safe, reliable person-centred care driving the best outcomes and experience",* while objective 2.4 is to *"Strengthen equitable outcomes and access for rural, regional and priority populations".*

Meanwhile, an identified short-term action under the National Roadmap for Improving the Health of People with Intellectual Disability is for

> *"States and territories to consider implementing measures that make public hospital and community health services accessible, trusted and safe for people with*

[10] Final Report of the Disability Royal Commission, Volume 6, p. 396.

intellectual disability. This could include guidance along the lines of 'The Essentials' produced by the Intellectual Disability Network of the NSW Agency for Clinical Innovation".

National Roadmap for Improving the Health of People with Intellectual Disability p.19.

As highlighted by the Roadmap and The Disability Royal Commission, continuing professional development in the health workforce is needed to ensure health professionals can effectively and respectfully communicate with a person with intellectual disability and to redress unconscious bias. Our experience is that the most effective way to address is this through co-designed training co-delivered by people with intellectual disability. Existing work on the National Roadmap to Improve the Health of People with Intellectual Disability includes compiling training resources, including some for co-delivery.

However, online learning is cheaper to implement and can be used state wide. CID has recently produced a series of e-learning modules, funded through an Information, Linkages and Capacity Building grant. They will be available within the HETI My Health Learning system by early 2024.

The Committee may therefore consider recommending the NSW Health Workforce Planning and Talent Development team to review the CID modules and consider if those on communication and reasonable adjustments might form helpful mandatory training for NSW Health staff.

A second important way to address skills shortage is through improved access to clinical placements in disability health services. Building training pathways for trainee clinicians and allied health professionals within the Specialised intellectual disability health services and mental health services would increase capacity within those teams, and broadly within the system overall as those trainees moved into other roles.

x. the role of multi-disciplinary community health services in meeting current and future demand and reducing pressure on the hospital system

Please see comment above for Terms of Reference # C, and also below for # H regarding the interface with NDIS. For people with disability, it is important access to NDIS-funded allied health supports does not become a reason for ineligibility for needed services through the health service.

People with disability and complex care needs will also greatly benefit from outreach from a care coordinator at the point of transition from adult care to other service.

G. Current education and training programs for specialist clinicians and their sustainability to meet future needs, including:

a. placements;

As outlined above, the Intellectual Disability Health Teams could be improved through providing trainee positions.

There is also a particular great need for targeted intellectual disability psychiatry training, with attractive remuneration. A previous scheme offered specific training Fellowships through the then Institute of Psychiatry. This boosted the supply of specialised psychiatrists at that time, and these psychiatrists remain a critical segment of the specialists currently working. However, there is a need to repeat the initiative over time.

H. New models of care and technical and clinical innovations to improve health outcomes for the people of NSW, including but not limited to technical and clinical innovation, changes to scope of practice, workforce innovation, and funding innovation

We realise that NSW Health has already identified that measurement is a "fundamental" part of Value Based Health Care, and that it is a problem that there are "many areas of the health system where the data needed to analyse outcomes is either not collected, available across the patient journey, or is not readily accessible"[11].

For value-based health care to be equitable, transparent and sustainable, it is important to capture data on the experience and outcomes of disadvantaged groups, especially those already identified as priority groups. The present data collection on the experience of people with intellectual disability highlights the need for innovative thinking and technical adjustments to administrative systems to achieve this.

At the present time, most information about the healthcare experiences of people with intellectual disability in NSW comes through research studies, anecdotal reports, or is inferred from the stark statistics about their health outcomes. Accessible patient-reported experience measures could identify points for improvement in the system much earlier. Presently, patient reported measures almost entirely miss this important group of healthcare users: complex surveys and online forms makes it difficult to capture feedback directly from people with intellectual disability. Meanwhile, it is difficult for a support person to complete these measures. The Committee may wish to ask each Health District

[11] NSW Health System priorities for value based healthcare research, October 2021, p. 10.

how they collect feedback from people with intellectual disability, and how many people with intellectual disability have actually provided such data in recent years, to identify successful practices if they exist.

Innovation in the funding of reasonable adjustment is also needed. As highlighted above, the Final Report of the Disability Royal Commission has highlighted the need for governments to

> *"review hospital (admitted and non-admitted care) and primary health care funding models to ensure these adaptations and supports can be implemented in all relevant settings". (Volume 6, p.31)*

It is our understanding that at present, some hospital systems disincentivise the provision of reasonable adjustments. For example, a longer appointment time is a highly effective adjustment for many people with intellectual disability to improve two-way communication. Improved communication enhances the quality and safety of the person's health care. However, where service booking structures and data collection are based only on volume of patients seen, allowing increased time may only be achievable by booking fewer people in for that day. With greater flexibility in the booking and data systems, reasonable adjustments could be recorded – to identify areas of good practice, and those in need of improvement.

Given that people with disability are an identified priority group in NSW Health's Future Health Report, we recommend NSW Health mandates that Districts collect and report on data relating to the provision of reasonable adjustments, as a measure of equity.

Improving the recognition of disability in health care records could also enhance provision of reasonable adjustments. Research using linked data examining hospital admissions for people with intellectual disability in NSW found that intellectual disability was recognised in in hospital records in less than a quarter of cases[12]. However, as any system needs to be opt-in, NSW Health systems need to accommodate reasonable adjustments even without disability flagged. Doing so would also serve a large number of other groups that may require adjustments.

[12] Walker, A. R., Trollor, J. N., Florio, T., & Srasuebkul, P. (2022). Predictors and outcomes of recognition of intellectual disability for adults during hospital admissions: A retrospective data linkage study in NSW, Australia. *PLoS One*, *17*(3), e0266051.

G. Any other matter reasonably incidental to a matter referred to in paragraphs A to H, or which the Commissioner believes is reasonably relevant to the inquiry.

There is currently a sharp demarcation between the NDIS and NSW Health system, which can compromise quality of care. This is most evident in policies that preclude a paid support worker staying with a person with disability who is in hospital. While a support person cannot be expected to provide any level of health care or monitoring, they can play an important role in supporting a person to communicate, and reporting changes in the person's behaviour which are atypical for the person. They also help the person with disability to cope with what can otherwise be a traumatic experience.

Recommendation 6.31 (b) of the Disability Royal Commission report was that:

> *The Australian Government Department of Health and Aged Care and state and territory counterparts should review all policies and protocols to ensure people with disability are permitted to be accompanied by a support person in any health setting. This should apply at all times, including when in-person healthcare restrictions are in place, such as during COVID-19.*

NSW Health should therefore review relevant policies and practices, provide clarity around issues of safety and responsibility, and work with the NDIA to ensure this recommendation is enacted throughout NSW Health settings.

Specific recommendations to address the issues raised including in relation to National structures or settings, including the National public hospital funding model and/or National Health Reform Agreement and the impact of aged and disability care in NSW public hospitals, where such recommendations would support or enhance any changes recommended by the Special Commission.

As part of its role in the National Health Reform, NSW Health should consider the actions for states outlined in the National Roadmap to Improve the Health of People with Intellectual Disability, along with health-related recommendations of the Disability Royal Commission. Working collaboratively with the National Centre of Excellence in Health Care for People with Intellectual Disability, and with health users with intellectual disability, NSW can lead reform to deliver better value health care which is in keeping with our commitments under the United Nations Convention on the Rights of People with Disability.

Summary of recommendations:

Recommendations are summarised here, in an order that makes sense.

1. NSW Health should act upon Recommendation 6.32 from the Final Report of the Disability Royal Commission, by:
   - Consulting with people with disability, including those with intellectual disability, to identify accommodations in health care provision,
   - Reviewing funding models to examine how they well they allow the provision of reasonable adjustments, and
   - Provide information about adaptations and supports in accessible formats.
2. Innovate change at the policy, process and systems level to encourage provision of reasonable adjustments in health care; and mandate that Health Districts collect and report on data relating to the provision of reasonable adjustments, as a measure of equity.
3. Ensure patients with intellectual disability can participate in patient reported outcome and experience measurements, through the provision of accessible surveys and other reasonable adjustments to support their participation in evaluation.
4. Improve the overall skills of the NSW Health Workforce to work with people with intellectual disability through:
   - Implementing *The Essentials* from the Agency for Clinical Innovation;
   - Promoting continuing professional development on communication reasonable adjustments. This could include the co-designed e-learning modules on these topics developed by CID, available within the My Health Learning system in early 2024.
5. Build capacity in specialised services through:
   - Expanding the network of Specialised Intellectual Disability Health, to see more patients and provide preventative medicine for those who need additional adjustments in a setting that allows a gradation of reasonable adjustments.
   - Building training pathways for trainee clinicians and allied health professionals within the Specialised intellectual disability health services and mental health services.
   - Providing specific Intellectual Disability Psychiatry Training Fellowships with attractive remuneration.
6. As part of its role in the National Health Reform, NSW Health should consider the actions for states outlined in the National Roadmap to Improve the Health of People with Intellectual Disability, and work collaboratively with the National Centre of Excellence in Health Care for People with Intellectual Disability to lead reform.
7. Address the sharp demarcation with NDIS to ensure people with disability can be accompanied by a support person in any NSW health setting, by:
   - reviewing relevant policies and practices to provide clarity around issues of safety and responsibility, and
   - working with the NDIA as needed to effect change.