Submission to the Select Committee into the Provision of and Access to Dental Services in Australia

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Background

Our submission focuses on the needs of adults with intellectual disability in accessing and affording dental services. We have responded to the inquiry Terms of Reference a, b, c, e, and i.

About NSW CID

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.

National Roadmap for Improving the Health of People with Intellectual Disability

As background to this submission, we draw the committee's attention to recent work relating to the National Roadmap for Improving the Health of People with Intellectual Disability. [1]

In response to stark evidence of fundamental health inequalities facing people with intellectual disability, former Health Minister Greg Hunt initiated a process to develop a National Roadmap. The Roadmap was developed by the Australian Government Department of Health in a highly collaborative way with the intellectual disability and health communities. CID were centrally involved in that process.

Mr. Hunt launched the Roadmap in August 2021 and it was adopted by the incoming Labor Government[2]. A Roadmap Implementation Governance Group (RIGG) is overseeing implementation of the Roadmap. This includes strong representation from the health and intellectual disability communities. CID is represented on the RIGG.

One of the seven elements of the Roadmap is Oral Health. The RIGG has specifically considered action in relation to oral health and prepared a paper *Oral Health Priority Actions - Implementation Recommendations*.[3]

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[1] The Roadmap is at available at https://www.health.gov.au/our-work/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability .
[2] Letter from Mark Butler, Minister for Health and Aged Care to CID dated 7/9/22, see attachment 1.

[3] Available at https://www.health.gov.au/committees-and-groups/roadmap-implementation-governance-group-rigg

That paper includes detailed priority recommendations within the following topics, denoted in that paper as D.S.4, D.S.1 and D.S.3., respectively:

Equal Priority 1: Expanding oral health promotion (D.S.4)

> *The Commonwealth to work with the disability sector to identify ways of implementing training in oral health as compulsory for disability support workers (Certificate IV), noting that it currently only contains elective content on this issue.*

Equal Priority 1: Increasing the volume of services (D.S.1)

> *Commonwealth Department of Health and Aged Care to:*
> - *work with the Australian Dental Association to promote the Child Dental Benefits Schedule (CDBS) to people with intellectual disability;*
> - *investigate the uptake of the CDBS by particular cohorts, including children with intellectual disability, to help inform the development of appropriate models of care;*
> - *explore the feasibility of financing a dental schedule under the Dental Benefits Act 2008 and other options for people with disability that better support complex and difficult services, such as in hospital services under general anaesthetic;*
> - *lead work with states and territories, peak oral health organisations and PHNs, including in the context of the proposed National Centre of Excellence in Intellectual Disability Health, to support the implementation of 'hub and spoke' models of care that facilitate upskilling, communication, and appropriate referral between centralised special needs dentists and community dental clinics.*

Priority 2: Expanding workforce training (D.S.3).

> ***Commonwealth Department of Health and Aged Care to:***
> - *work with deans of dental schools on courses for dentists, dental therapists and hygienists to specialise in oral health care for people with disability*
> - *work with the Australian Dental Association to develop continuing professional development modules.*

Excerpts from Roadmap Implementation Governance Group Oral Health Priority Actions – Implementation Recommendations.

We suggest that the committee ask the Australian Government Department of Health and Aged Care to give evidence in relation to progress in action on the Roadmap end the recommendations from the RIGG. We also ask the committee to stress the importance of action on these issues in its report.

CID's response to Inquiry Terms of Reference

A. The experience of children and adults in accessing and affording dental and related services

The National Roadmap summarises the key for people with intellectual disability accessing dental care:

> *The majority of people with intellectual disability face barriers, such as cost and access to specialist dental services. Some people with intellectual disability need to attend hospital for dental care as they cannot tolerate dental interventions without general anaesthetic.*
>
> *A lack of dentists with adequate skills in treating paper with disability is the most frequent reported problem in obtaining dental care, followed by cost.*
>
> *National Roadmap for Improving the Health of People with Intellectual Disability, p.27*

To highlight some of these barriers, below we describe the recent experiences of four people with disability, all of whom live within a 2 hour drive of Sydney. They have all given permission to share their stories with you.

Although their names have been changed, there is still a reasonable likelihood that someone could recognise them based on the histories described. Therefore, in the interests of privacy, we request that pages 6 to 9 not be made publicly available.

The four stories described above certainly highlight difficulties with regards both access and affordability for people with intellectual disability.

Affordability:

Affordability of dental care is a major issue for many Australians on a low income. For those whose disability or health conditions adds complexity to their oral health care, sourcing this care privately would be prohibitively expensive.

From the stories, we see:

- Marcus's debt relating to private dentistry meant he did not access care when needed. Marcus says regarding private dentists: *"The only thing that goes through my head when booking is the cost".*
- Kai's complex needs necessitated quick action for a potentially life-threatening issue, so he chose to pay for private dental on that occasion. But it *"cost an arm and a leg"* and is not a cost he can manage for more routine dental care.
- Felicity can not afford a private dentist while she waits for public dental care.

Access:

Access is particularly poor for those requiring a dentist with expertise dealing with people with complex needs. We see this in the stories above:

- It would appear that Eleanor's need for general anaesthetic and the resulting delay was determined by the physical inaccessibility of an x-ray machine in her local public clinic. Her mother Audrey is unaware of anywhere else that Eleanor could go for dental care within their community.
- Felicity's previously success coping with tooth extraction suggests she might cope with at least some dental care without anaesthetic. The need for general anaesthetic means she's instead waited close to another year so far.
- Kai believes that a major barrier to his accessing dental care is that so few dentists are willing to pay the additional insurance to deal with someone at high risk of aspiration of fluids.

Improving access to dentists with expertise working with patients with complex needs will require both:

- equipping mainstream dentists cater for people with disability in their local community, including through providing reasonable adjustments, and
- increasing the number of Special Needs Dentists[4].

[4] "Special Needs" is not a preferred term for CID, due to the historical paternalistic use of this term in relation to people with disability. Special Needs Dentists do not only provide services for people with disability but also other patients with complex care needs, such as those experiencing domestic violence, homelessness, cancer, or other physical or mental health conditions.

B. The adequacy and availability of public dental services in Australia

All four of the stories described in section A also highlight the inadequacy of public dental services.

Excessive wait times:

Kai, Eleanor and Felicity's stories all involved excessive wait times for an initial appointment and/or treatment. The NSW Health *Priority Oral Health Program (POHP) and Waiting List Management* policy recommends that a person with intellectual or physical disability should have a maximum wait time of 6 months for assessment. The same policy recommends a maximum wait time for treatment of 6 months for patients with 'Special Needs'.

Healthy people with no specific dental problems are recommended to see a dentist every 6-12 months for a check-up[5]. The people we have described who rely on public dental care have waited longer than this, despite falling into a higher triage category according to policy.

Problematic triage and poor communication with patients

- Eleanor waited for months for treatment despite evidence of pain; the public service would not combine the dental work with addressing her hernia with no explanation given to her mother Audrey; and there was little information provided to Eleanor and Audrey following her procedure.
- Kai was passed between public dental services and is still awaiting an initial appointment more than 6 months later.

Access to information

The stories also highlight the difficulties that people with intellectual disability may have accessing information relating to public dentistry:

- Marcus was originally not aware of the Oral Health Fee for Service Scheme vouchers and so went years without dental care.
- Felicity and her support worker do not know how they can find out more information, or how to report that her teeth are getting worse whilst on the wait list.
- Audrey told us Eleanor received a letter asking to confirm her need for public dentistry. To remain on the wait list involved mailing back a response. This would not be accessible to many people with intellectual disability, and not all people with disability have support.

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[5] https://www.healthdirect.gov.au/dental-check-up

Public funding of private dental care

On a happier note, Marcus's story shows that publicly funded systems which give a choice of dentists, including private dentists, can be far more efficient and result in less anxiety for the person. However, other people with disability who may be eligible for the NSW voucher scheme have reported to us that they are not aware of them.

The need to consider and fund reasonable adjustments

Any arrangement to fund private dental care through government schemes needs to allow dentists to provide reasonable adjustments to people with disability. Reasonable adjustments that could help a person to cope with dental care better may include things like:

- breaking an appointment into multiple appointments
- cleaning smaller sections at a time, with pauses to breathe in between
- allowing increased time for communication, including time to allow support for decision-making.

These adjustments result in increased time spent completing a procedure. If a dentist passes the additional cost onto the patient, then people with disability are effectively being charged more for the same procedure than people without disability. We have heard of cases where the cost of basic dental care was so high, it is likely the additional cost has indeed been passed on to the person with disability.

Anecdotally, we have also been told of cases where people with disability are referred to Special Needs dentists when all that is needed to meets their needs is additional time. It would be far more efficient and fair for people with disability to be seen by a dentist of their choice, and for the extra time needed for reasonable adjustments to be compensated appropriately through public sources. We have a Medicare provision for 'Long consultations' with doctors when they are needed. A similar approach would encourage dentists to provide reasonable adjustments, and likely increase access to dentists for people with disability.

C. The interaction between Commonwealth, state and territory government legislation, strategies and programs in meeting community need for dental services

As outlined above, there is already substantial work relating to the Roadmap, identifying the most fruitful ways for governments to work together to improve oral health care for people with intellectual disability.

E. The social and economic impact of improved dental healthcare

> *Studies have shown that people with intellectual disability have poor oral hygiene and greater prevalence and severity of periodontal disease than the general population. The consequences of neglecting oral health are serious*

> *and include pain, infection and loss of teeth, leading to functional difficulties with diet, speech and behaviour as well as severe systemic health issues.*
>
> *National Roadmap for Improving the Health of People with Intellectual Disability, p.27.*

There is a wealth of evidence emerging which identifies oral health problems as a modifiable risk factor for numerous other health conditions[6].

People with intellectual disability have substantially worse health outcomes than people without disability. It makes sense, then, to reduce the risk of poor health where possible, including through addressing dental care needs adequately. To do so will require both equipping the mainstream dentistry workforce, and building the numbers of special needs dentists.

G. Pathways to universal access to dental services

> "*If it was available, I'd already have seen them"* (Marcus).

CID supports universal access to dental services.

Given the difficulties faced by many people with disability accessing dental care in the community, it is important these services are inclusive, accessible and that accessible information about them is readily available.

I. Workforce and training matters

The stories we have included highlight a clear need for professionals involved in the oral health care of people with ID to receive better training to provide better quality care for people with disability, including the provision of reasonable adjustments.

For dentists:

- Eleanor's anaesthetic could have been combined with other needed procedures, but the staff involved did not facilitate this even when asked
- Felicity and her support worker do not know if there is a way to clean her teeth better, or a product she could use. The dentist she saw using her voucher could have provided this level of patient and supporter education
- Felicity is not fully aware of why general anaesthetic is needed, suggesting that reasonable adjustments to allow her to make an informed decision have not been implemented. Furthermore, in the nearly 12 months she has spent waiting for the procedure so far, she might have worked with a psychologist to address her anxiety and attempted dental care without general anaesthetic. No one involved in her dental care suggested this.

[6] See Patel et al. 2021 for a review.

For the broader public dental workforce:

- Eleanor was put through a stressful situation just to discover that her wheelchair was incompatible with the x-ray machine – something that could have been identified before she was even offered an appointment there.
- The ancillary staff who offered Kai an appointment could have asked about risk factors that would preclude him using their service.

For GPs:

- Kai's GP did not know where to refer him for dental care
- Marcus was avoiding the public dental clinic due to his poor prior experiences there, but could not afford private dental care. It is unfortunate that his GP did not ask about his dental care and if he was aware of the NSW Oral Health Fee for Service Scheme earlier.

For disability workers:

- There is a need for support workers to receive education in oral health care so that they can support their clients to maintain optimal oral hygiene.

Recommendations

Recommendation 1:

The Australian Government work with states and territories to implement all short and medium term key actions relating to Oral health from the *National Roadmap for Improving the Health of People with Intellectual Disability*, with immediate attention paid to the priorities identified in the *Roadmap Implementation Governance Group Oral Health Priority Actions – Implementation Recommendations*.

Recommendation 2:

In any system for government-funded access to private dental care, when determining permissible service costs, consider both the procedure and the reasonable adjustments that allow an individual with disability to access it in their local community.

Recommendation 3:

Ensure that accessible information regarding public dentistry options is available in both print and hard-copy formats. This should include how to make an appointment and what to do if your condition worsens whilst awaiting an appointment.

References

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Attachment 1: Letter from Mark Butler, Minister for Health and Aged Care, to CID dated 7 September 2022

The Hon Mark Butler MP
Minister for Health and Aged Care

Ref No: MC22-014817

Mr Jim Simpson
Senior Advocate
Council for Intellectual Disability

Dear Mr Simpson Jim

Thank you for your correspondence regarding election commitments on the health of people with intellectual disability. I apologise for the delay in responding.

It is an honour to be appointed Minister for Health and Aged Care in the Albanese Government.

In a prosperous country like ours, there is no more important role than ensuring access to affordable and high-quality health and medical care.

Our health system has excellent foundations and world-class medical professionals but the pandemic has highlighted the need for new investment and energy in primary care, including strengthening the Medicare system.

The Australian Government recognises that people with intellectual disability have significantly worse health outcomes than the general population, and that concerted action is required to address this.

During the election campaign, I was pleased to announce that the Government would match the former Government's commitment to establish a National Centre of Excellence in Intellectual Disability Health (National Centre). This builds on our commitment to implement the National Roadmap for Improving the Health of People with Intellectual Disability (Roadmap). The National Centre is fundamental to successful delivery of the Roadmap.

I am very conscious of the need to ensure that the competitive grant opportunity for the National Centre is completed in 2022-23. This will need to reflect the outcome of the Government's consideration of longer-term funding options. I expect announcements will be made in the October 2022 Budget.

The $20 million allocated through the Medical Research Future Fund from 2024-25 is also a key commitment to improving the health of people with intellectual disability that the Government has affirmed.

Parliament House Canberra ACT 2600

I am pleased that the Council for Intellectual Disability is a member of the Roadmap Implementation Governance Group. Thank you for your continued participation in this Group. The Department of Health and Aged Care will continue to work with the Group to provide further advice on implementing other actions under the Roadmap, to build on the important work that is already under way.

I look forward to working with you and other stakeholders, to further deliver on our healthcare commitments over the coming term.

Thank you for your offer to meet again. My office will be in contact to arrange this.

Yours sincerely

Mark Butler

7/9/2022

cc: The Hon Ged Kearney MP, Assistant Minister for Health and Aged Care