

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

This Joint Submission was prepared by

Australian Federation of Disability Organisations (AFDO)

Children and Young People with Disability Australia (CYDA)

Down Syndrome Australia

Inclusion Australia



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About us

Down Syndrome Australia

Down Syndrome Australia is the National peak organisation for people living with Down syndrome and their families.



Our purpose is to influence social and policy change and provide a national profile and voice for people living with Down syndrome. Our vision is an Australia where people living with Down syndrome are valued, reach their potential, and enjoy social and economic inclusion.

People with Down syndrome are at the centre of all the work that we do. All our work is informed by the United Nations Convention on the Rights of Persons with Disabilities. We work together with state and territory organisations to achieve our vision.

Australian Federation of Disability Organisations (AFDO)

Since 2003, the Australian Federation of Disability Organisations (AFDO), a Disabled Peoples Organisation (DPO) and Disability Representative Organisation

(DRO), has been the recognised national peak organisation in the disability sector, along with its disability specific members, representing people with disability. AFDO's mission is to champion the rights of people with disability in Australia and support them to participate fully in Australian life.



Australian Federation of Disability Organisations

With our thirty-two member organisations, we are the only national peak representing disability specific and cross disability-based communities with a total reach of over 4 million Australians.

AFDO continues to provide a strong, trusted, independent voice for the disability sector on national policy, inquiries, submissions, systemic advocacy and advisory on government initiatives with the Federal and State/Territory governments.

We work to develop a community where people with disability can participate in all aspects of social, economic, political, and cultural life. This includes genuine participation in mainstream community life, the development of respectful and valued relationships, social and economic participation, and the opportunity to contribute as valued citizens.

Children and Young People with Disability Australia (CYDA)



Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA has an extensive national membership of more than 5,000 young people with disability, families and caregivers of children with disability, and advocacy and community organisations.

Our vision is that children and young people with disability are valued and living empowered lives with equality of opportunity; and our purpose is to ensure governments, communities, and families, are empowering children and young people with disability to fully exercise their rights and aspirations. We do this by:

- driving inclusion
- creating equitable life pathways and opportunities
- leading change in community attitudes and aspirations
- supporting young people to take control
- calling out discrimination, abuse, and neglect

CYDA's work is informed by the insights and lived expertise of young people and families/caregivers who participate in our survey work, youth focus groups and National Youth Disability Summit 2022 and 2023 co-facilitated by young people with disability.

Inclusion Australia

Inclusion Australia is the national Disability Representative Organisation (DRO) representing the rights and interests of Australians with an intellectual disability and their families.



Founded in 1954, our mission is to work to make sure people with an intellectual disability have the same opportunities as people without disability. We have state members in New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia:

- Council for Intellectual Disability (CID)
- Parent to Parent (P2P)
- South Australian Council on Intellectual Disability (SACID)
- Speak Out Association of Tasmania (Speak Out)
- Victorian Advocacy League for Individuals with Disability (VALID), and
- Developmental Disability WA (DDWA)

Since September 2021 we have had a Northern Territory team based in Darwin. Our work in the Northern Territory is informed by a Local Steering Group that includes representatives from advocacy and other territory-based organisations.

Acknowledgements

The authors of this submission acknowledge the Traditional Owners of the land on which this publication was produced. We acknowledge the deep spiritual connection to this land of Aboriginal and Torres Strait Islander peoples, and we extend our respects to community members and Elders past, present.

The authors also wish to recognise and stand in solidarity with the efforts of self-advocates who have courageously told their stories and worked tirelessly over the years for equality and human rights for all.

We deeply thank all the people who shared their stories, experiences and expertise about accessing dental care. We acknowledge their generosity in sharing their lived experience and insights which are so important in informing this submission.

We also acknowledge people with disability, particularly those individuals that have experienced or are continuing to experience violence, abuse, neglect, and exploitation. We also acknowledge their families, supporters, and representative organisations and express our thanks for the continuing work we all do in their support.

About this submission

The evidence and recommendations in this submission have been drawn primarily from the stories, experiences, and expertise of people with disability and their family members. Given the lack of data and research available on the oral health needs and experiences of people with disability, it is a significant strength of this submission that it includes the lived experience and expertise of people with disability and their family members. This is crucial evidence that is often missing from the datasets we do have on the oral health of Australians: it provides critical insights in understanding the access to and provision of dental services in Australia.

The evidence contained in peoples' lived experience, which was generously shared with our organisations, is further substantiated in this submission by available national and international datasets and academic literature, plus our organisations' collective work in health advocacy for people with disability.

This submission highlights oral health issues of people with disability from the perspective of the person and their individual experiences and needs, and how these needs can be more effectively met by the dental sector. Diagnosis can be important to dental care—particularly for people whose specific conditions have comorbidities associated with poorer oral health outcomes. Yet, by and large, the barriers to oral health experienced by people with disability relate to systemic issues (economic, social, political and cultural), and not a person's disability.

Executive Summary

In Australia, people with disability are shut out from receiving the dental care they need. Australians with disability have poorer oral health, greater unmet treatment needs and less regular dental attendance than the rest of the Australian population.¹

Oral health is a proxy for overall health: both are interconnected and influence the other. Not only is poor oral health linked to several chronic diseases, including stroke and cardiovascular disease, it is intimately connected to a person's mental wellbeing.

When people can't get the dental care they need, or don't have access to resources to assist them maintaining their own oral health as a preventative measure, it leads to debilitating social impacts that stop people from living the kind of life they want.

Stories shared by people with disability in this submission demonstrate the negative attitudes; inaccessible and unsupportive communication; denial of basic support needs; economic, emotional, and physical cost; and long wait times they experience when trying to access the dental care they need.

Despite the establishment and growth of Special Needs Dentistry (SND) as one of Australia's newest dental disciplines about 30 years ago, the Australian Society of Special Care in Dentistry (ASSCID) remains a very small group of just over 50 practitioners. Today, there are less than 25 dentists across Australia who specialise in SND.

There is a massive and unsustainable demand for dentists with training in SND in Australia, yet **many of those who are trying to access SND specialists could access dental care in general settings if reasonable adjustments were made and inclusive practices were systematically implemented.**

This demand of SND practitioners itself reveals the significant **systemic changes that are needed within general dentistry to make dental care accessible to and inclusive of people with a disability.**

As this submission demonstrates, people with disability face a number of entrenched attitudinal and systemic barriers that significantly impact the quality and equity of dental treatment they receive.

In this submission we present a range of evidence that demonstrates the impact of these barriers on peoples' lives, plus a suite of actionable solutions that would ameliorate these barriers, and make general dental care more inclusive of people with disability.

The lived experience and expertise shared by the people our organisations represent have informed the recommendations that we believe must be actioned to ensure Australia can meet its obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

¹ Lopez Silva, C. P., Singh, A., Calache, H., Derby, H. A., and Borromeo, G. L. (2021). Association between disability status and dental attendance in Australia—A population-based study. *Community Dentistry and Oral Epidemiology* 49(33): 33-39. <https://doi.org/10.1111/cdoe.12571>;

Pradhan, A., Slade, G., Spencer, A. (200()) Access to dental care among adults with physical and intellectual disabilities: residence factors. *Australian Dental Journal* 54(3):204-211.

Recommendations

1. Improve data collection on the oral health of people with disability

This was listed as a goal in *Healthy Mouths Healthy Lives: Australia's National Oral Health Plan 2015-2024* in relation to the priority population of people with additional or specialised needs, which aimed to “collect national baseline and ongoing data to more accurately identify the numbers of people with specialised health care needs, their oral health status and treatment needs.”²

However, it is not clear that this has occurred.

We strongly recommend this goal be actioned, particularly given the work being done by the Department of Social Services to pilot and develop a National Disability Data Asset (NDDA). Oral health data, including qualitative data through the lived experience of people with disability, is critical information that should be included within any data linkages project like the NDDA.

As a starting point for Government, we recommend making alterations to the National Child Oral Health Study and the National Survey of Adult Oral Health to include specific data collection on children and adults with disability. Data must also capture disability type, as well as other intersections such as Cultural and Linguistically Diverse (CALD) or Aboriginal and Torres Strait Islander people with disability.

2. Include dental care as part of Medicare for Australians with disability

Preventative dental treatment, plus a number of common dental procedures, must be added to Medicare for people with disability to considerably reduce or eliminate the cost of seeing a dentist. Disability may be inclusive of, but not limited to, neurodivergence, mental illness, intellectual disability, chronic illness, sensory disability and physical disability.

Australia's *Healthy Mouths Healthy Lives: National Oral Health Plan 2015-2024* flagged the expansion of the Child Dental Benefits Schedule (CDBS) to incorporate adults within the Plan's 'priority populations', which included people who are socially disadvantaged and people with additional or specialised health care needs. We recommend this measure be adopted as a matter of urgency, especially since there is evidence to suggest that the CDBS did result in an increased access to dental services and improved visiting patterns in low-income households.³

Over time, work must be done to develop relevant economic modelling and planning to devise a path forward to enable the full inclusion of dental as part of Medicare for people with disability, as well as other priority groups identified in the *National Oral Health Plan 2015-2024*.

² Department of Health and Aged Care. *Healthy Mouths Healthy Lives: Australia's National Oral Health Plan 2015-2024*. Retrieved from: <https://www.health.gov.au/resources/publications/healthy-mouths-healthy-lives-australias-national-oral-health-plan-2015-2024?language=en>

³ Stormon, N., Do, L., & Sexton, C. (2022). Has the Child Dental Benefits Schedule improved access to dental care for Australian children? *Health & Social Care in the Community*, 30. <https://doi.org/10.1111/hsc.13803>

3. Sustainably invest in Domiciliary dental care (DDC)

DDC should be sustainably funded across Australia, with a focus on regional, rural and remote areas, to allow people to receive subsidised dental treatment at home to ameliorate the costs and administrative burden of travelling long distances to see a dentist.

4. Sustainably invest in Special Needs Dentistry (SND) and upskill general dentists to treat people with disability

This can be achieved by including measures in Australia's next 10-year National Oral Health Plan to promote the systematic upskilling of dentists in treating people with a disability and generally invest in SND practices at a tertiary level.

While there is a severe shortage of dentists trained in SND, we emphasise in this submission that many people with disability—including many people with complex needs—can access care in the community through general dental practices if reasonable adjustments are made to ensure equity of access to care. We acknowledge that SND is a critical discipline that should be invested in and promoted, and that it should be reserved for those with the most complex support needs.

A reasonable adjustment refers to any form of support, assistance or adjustment to practice that is necessary, possible and reasonable to eliminate the barriers that inhibit people with disability from getting the dental care they need. We highlight several examples of what this might look like for different people in this submission. We also note that the requirement to make reasonable adjustments is implicit in the requirement to avoid indirect discrimination against a person with disability under section 6 of the *Disability Discrimination Act 1992*.

The upskilling of dentists to treat people with disability was not included in sufficient detail in the current *National Oral Health Plan 2015-2024*. This should be added as a matter of urgency, and actualised through collaboration between Government, the dental healthcare sector, and the disability support sector.

The disability support sector, in this instance, refers to Disability Representative Organisations, NDIS and non-NDIS service providers, self-advocacy organisations, and advocacy organisations across states and territories. We also recommend working with the Department of Health and Aged Care team responsible for the Curriculum development in the health of people with an intellectual disability.

University fee subsidies or other incentives should also be implemented to encourage more students to undertake training in SND, given that there are less than 25 practicing dentists in Australia with training in SND.

5. Promote interprofessional education and practice between Special Needs Dentistry (SND), general dental practitioners, general medicine, the disability support sector, and people with disability themselves to increase the capacity of general dentists to treat people with disability

Dental care is too often siloed from general healthcare. The upskilling of dentists must also involve collaboration with health professionals across the health sector as a critical pathway to achieving greater interdisciplinary communication and promotion of awareness of the oral, and general, health needs of people with disability.

Importantly, this must also happen in collaboration with the disability support sector (as defined in recommendation 4), and in particular, in collaboration with people with disability, who are of course the experts in their own lives. As described in this submission, the National Roadmap for Improving the Health of People with Intellectual Disability highlights this need and provides an opportunity for systemic change.

This enhanced collaboration should support the embedding of vital human rights-based provisions to dental care outlined in other recommendations, including the promotion of knowledge and practice models of Supported Decision Making and Positive Behaviour Support as part of oral health care, as per recommendation 10.

6. Sustainably fund rights-based training for dentists and allied health professionals that is co-designed and co-led by people with disability and family members to promote understandings of disability grounded in lived experience and inclusive practice

The current National Safety and Quality Health Services (NSQHS) Guide for Dental Practices and Services (the Guide) contains several significant gaps when it comes to setting a standard of quality and safety in healthcare for people with disability.

We strongly recommend revising the NSQHS Guide to include measures that promote rights-based, inclusive practice grounded in the lived experience of people with disability. This should be a basic standard of care that will guide all dental practitioners across Australia in their interactions and treatment of people with disability to ensure that all people receive care that upholds their human rights and dignity.

7. Improve access to a range of sedation pathways and provide better support for people who may require sedation, with the use of General Anesthesia (GA) reserved as a last resort

While there are a range of reasonable adjustments that could be put in place to avoid the need for sedation, many people with disability—particularly for people with an intellectual disability or people with complex support needs—require support through use of sedation to minimise distress or anxiety around health procedures, as well as provide more equitable access to dental care.

People with disability may need a different sedation approach to others, and access to a range of sedation pathways must be provided.

This does not automatically mean the use of General Anesthesia (GA). While GA may be necessary for some, other less intrusive forms of sedation must be available and all options presented to a person and their supporters in a way that makes sense to them, enabling the person to make their own decisions about, and provide informed consent to, the sedation approach to the maximum extent possible.

8. Provide communication and information in a way that makes sense to the person

Make an addition to the National Safety and Quality Health Services (NSQHS) Guide for Dental Practices and Services that outlines the need to support all peoples' unique communication styles, including by making Easy Read information available to the person, together with sufficient time to work through the information with whatever supports the person needs.

Communicating and providing information in a way that makes sense to the person is also intimately connected to, and flows from, a way of thinking and relating that is grounded in respect and a commitment to upholding the human rights of people with disability, reflecting the United Nations Convention on the Rights of Persons with Disabilities, to which Australia is bound.

9. Ensure use of Assistive or Augmentative Communication (AAC) tools are respected and provided where a person uses them

Make an addition to the National Safety and Quality Health Services (NSQHS) Guide for Dental Practices and Services that outlines the need to support all peoples' unique communication styles, including by respecting peoples' use of AAC tools and ensuring these are made available to people wherever and whenever necessary.

10. Ensure all people have access to Supported Decision Making at the dentist as a pathway to the provision of genuine informed consent and choice and control over their oral health

Do this by embedding the Australian Law Reform Commission (ALRC) National Decision-Making Principles within the forthcoming 10-year *National Oral Health Plan* and a revised version of the National Safety and Quality Health Services (NSQHS) Guide for Dental Practices and Services.

Background

Timely, affordable, and accessible dental care is a critical aspect and enabler of general health and mental wellbeing.

Oral health is a proxy for overall health: both are interconnected and influence the other. Not only is poor oral health linked to several chronic diseases, including stroke and cardiovascular disease, it is intimately connected to a person's mental wellbeing. When people can't get the dental care they need, or don't have access to resources to assist them maintaining their own oral health as a preventative measure, it leads to debilitating social impacts that stop people from living the kind of life they want.

People with disability, and particularly people with an intellectual disability experience overall poorer health outcomes compared to people without disability.

This has been outlined in detail in the National Roadmap for Improving the Health of People with Intellectual Disability (the Roadmap),⁴ which is an Associated Plan to *Australia's Disability Strategy 2021-2031*.⁵ The Roadmap describes the ways in which people with an intellectual disability experience significantly poorer health outcomes compared to other people with disability and people without disability, including:

- More than twice the rate of avoidable deaths
- Twice the rate of emergency department and hospital admissions
- Substantially higher rates of physical and mental health conditions—while simultaneously lower rates of detection of illness, particularly of mental illness
- Significantly lower rates of preventative healthcare and underdiagnosis of chronic and acute health conditions.⁶

Given that oral health is intimately connected to a person's general health and wellbeing, it is critical to consider this context. Oral health, and dental care, are whole-of-life issues that have significant consequences for a person's overall health and wellbeing: these aspects of health must be understood in connection, and not in silos.

⁴ National Roadmap for Improving the Health of People with Intellectual Disability. 2021. Department of Health and Aged Care. Retrieved from: <https://www.health.gov.au/our-work/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability>

⁵ Australia's Disability Strategy 2021-2031. Retrieved from: <https://www.disabilitygateway.gov.au/document/3106>

⁶ Inclusion Australia. (2020). Inclusion Australia's Response to the issues paper on healthcare for people with cognitive disability. p. 4. Retrieved from: https://www.inclusionaustralia.org.au/wp-content/uploads/2021/10/Our-Submissions_2020_08_Submission-to-the-DRC-on-healthcare-for-people-with-intellectual-disability.pdf

Inclusion Australia. (2020). Submission to the Disability Royal Commission – The Omnibus. p. 51-54. Retrieved from: <https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-the-omnibus/>

Reflecting the above statistics, research shows that people with disability, and particularly those with an intellectual disability, also have poorer oral health, greater unmet treatment needs and less regular dental attendance than the rest of the Australian population.⁷

These trends show that access to and provision of dental services in Australia is inadequate for people with disability, and there are several important changes to existing policy frameworks that need to be addressed to ensure Australia can meet its human rights obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Overview of barriers to accessing dental care

Stories shared by people with disability in this submission demonstrate the negative attitudes; inaccessible and unsupportive communication; denial of basic support needs; economic, emotional, and physical cost; and long wait times they experience when trying to access the dental care they need.

For people with disability who live in regional, rural and remote areas, there are even greater systemic barriers to accessing dental care.

Despite the establishment and growth of Special Needs Dentistry as one of Australia's newest dental disciplines about 30 years ago, the Australian Society of Special Care in Dentistry (ASS CID) remains a very small group of just over 50 practitioners.⁸

Special Needs Dentistry (SND) is broad in scope and aims to treat people with a range of needs. The aim of this discipline is to support the oral healthcare needs of “people with an intellectual disability, medical, physical, or psychiatric conditions that require special methods or techniques to prevent or treat oral health problems”.⁹ Patients may include those living with disability, people experiencing homelessness or domestic violence, people who may be living with medical conditions like cancer, or people living with a range of mental health conditions.

Today, there are approximately 4.4 million Australians living with disability. There are **24 practicing special needs dentistry specialists across Australia**. Those specialists only reside in some, but not all, capital cities.

Yet, as Dr Avanti Karve—President Elect of the Australia and New Zealand Academy of Special Needs Dentistry (ANZASND)—points out,

⁷ Lopez Silva, C. P., Singh, A., Calache, H., Derby, H. A., and Borrromeo, G. L. (2021). Association between disability status and dental attendance in Australia—A population-based study. *Community Dentistry and Oral Epidemiology* 49(33): 33-39. <https://doi.org/10.1111/cdoe.12571>;

Pradhan, A., Slade, G., Spencer, A. (2000) Access to dental care among adults with physical and intellectual disabilities: residence factors. *Australian Dental Journal* 54(3):204-211.

⁸ Disability Oral Health Collective (DOHC), Your Dental Health Project (Inclusion Melbourne) team and Australasian Academy of Paediatric Dentistry (AAPD). 2020. Joint submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from: [Royal-Commission-Oral-Health-Disability-YDH-ASSCID-DOHC-20200210.pdf \(inclusionmelbourne.org.au\)](https://www.inclusionmelbourne.org.au/Assets/DOHC-20200210.pdf) p. 6.

⁹ Royal Australasian College of Dental Surgeons. Specialist Dental Practice 2014. 2015. Retrieved from: http://www.racds.org/RACDSNEW_Content/Education/Specialist_Dental_Practice.aspx. Accessed May 2, 2015.

“Not all patients with special health needs need specialist care. Many can access care in the community if ‘reasonable adjustments’ are made to ensure equity of access to care. We need more interest from general dental practitioners ... so specialist practice is reserved for the most complex and medically unwell”.¹⁰

Many people with disability experience tremendous difficulty finding dentists who are willing to treat them, and as the evidence within this submission demonstrates, this is not only due to the lack of dentists with training in SND.

When people do get access to dental care, they face any number of entrenched attitudinal and systemic barriers, which significantly impact the quality and equity of dental treatment people with disability receive.

When trying to understand the nature of these barriers, it is crucial to listen to the voices of those who experience them. Yet the views, expertise and experiences of people with disability are by and large lacking in the literature—which is also why the Case Studies in this submission, and the evidence therein, is so critical.

One significant study from the UK has attempted to bridge this gap.¹¹ Interviews with people with an intellectual disability¹² and their supporters were analysed, and their responses suggested there were six key barriers people experience when trying to access dental care. Although this research comes from a UK context, comparable Australian research suggests these barriers are equally prevalent in an Australian context.

The barriers identified by that study, and how they may be understood in an Australian context, are as follows:

1. Choice and access

This describes the way that people with disability do not have sufficient freedom of choice of services. Often, people with disability and their supporters are constrained in their choice of service, most often because of geographical or cost factors, rather than being able to choose a service that would best suit their needs.

2. Physical access to services

This refers not only to whether the external and internal of a building or space is accessible, but the accessibility of transport to that site. For many, this may mean relying on a family member or paid supporter to assist them in getting to a service, or relying on public transport. For those living in regional or remote places, getting to a service that may be many kilometres away presents a range of difficulties.

¹⁰ Australian Dental Association. April 2022. “Special Needs Dentistry spotlight (part 1)”. Retrieved from: [https://www.ada.org.au/News-Media/News-and-Release/Latest-News/Special-needs-dentistry-spotlight-\(part-1\)-1504202](https://www.ada.org.au/News-Media/News-and-Release/Latest-News/Special-needs-dentistry-spotlight-(part-1)-1504202)

¹¹ Owens, J., Mistry, K., and Dyer, T.A. 2011. Access to dental services for people with learning disabilities: Quality care? *Journal of Disability and Oral Health* 12(1): 17-27.

¹² This study used the term ‘learning disabilities’, which is often used in the UK to refer to intellectual disability. Today, ‘intellectual disability’ is becoming the more commonly used term internationally.

3. Adaptability of services to needs

This means the extent to which services are available at the right time; fit personal and family schedules; and are dependable.

The study gave a poignant example of the ways adaptability presents as a barrier: accessing a dentist when in pain can be difficult for someone who has complex communication needs. In this instance, the person often relies on a family member or supporter to pick up on cues and communicate their needs to the dental practitioner. In this situation, the family member or supporter is a gatekeeper to care, and whether or not that person is listened to, trusted and valued—coupled with the extent to which the person with disability's communication needs are met and valued by dental professionals—has a considerable impact on the quality of care the person with disability will receive.

4. Attitudes of dental professionals

Unfortunately, the attitudes of many dental professionals in Australia present a barrier to people with disability being free to access the dental care they need.¹³ This also results in a reluctance among dental professionals to treat people with disability in general.¹⁴

In the study, many people with an intellectual disability reported that dental services excluded them because of the way their needs were defined in terms of their disability. There is a tendency within medical professionals broadly to think of, and relate to, people with disability through an outdated 'medical model' of disability. This means people are understood rigidly through the lens of disability as a 'problem' that belongs to the individual, rather than understanding the social, economic, attitudinal, cultural and political factors that create and compound peoples' experience of disability.

As the author of the UK study writes, when dental practitioners see and relate to people with disability in this medicalised way, people with disability "became objects and part of a group, not individuals in their own right".

For services to be accessible to people with disability, it is critical that the attitudes of dental practitioners are grounded in human rights and genuinely value the experience, voice and dignity of the person—which means listening to the person; respecting and responding to their support needs; and centering them in decisions about their own health and bodies. When this does not happen, not only does it become a barrier to people accessing the care they need, it also can result in discrimination and breaches of human rights.

¹³ Pradhan, A., Slade, G.D., Spencer, A.J. 2009. Factors influencing caries experience among adults with physical and intellectual disabilities. *Commun Dent Oral Epidemiology* 37(2):143–54;

Pradhan A, Slade GD, Spencer AJ. 2009. Access to dental care among adults with physical and intellectual disabilities: residence factors. *Aust Dent Journal* 54(3):204–11.

¹⁴ Pradhan A, Spencer A, Slade G. 2007. Factors influencing oral health of adults with physical and intellectual disabilities in various living arrangements. *Australian Dental Journal* 52(S4).

As the Case Studies in this submission shows, such attitudes can also present traumatic experiences for people with disability and their family members.

5. Continuity of care

This highlights the importance of building a relationship with the person with disability and their supporters. When people do not receive continuity of care—meaning having to wait long periods between appointments; seeing a different dentist or allied health professional at each appointment; not having enough time to get to know a person and communicate their support needs—this presents a barrier to accessing the dental care a person needs.

6. Financial costs

As described in detail in the following section on Key Issues, dental care is generally unaffordable for many Australians, particularly people with disability, who are more likely to have a low socioeconomic status than people without disability.¹⁵

The structural reasons for this are deeply entrenched and far reaching. This is discussed on page 21 of this submission.

¹⁵ Lopez Silva, C. P., Singh, A., Calache, H., Derby, H. A., and Borromeo, G. L. (2021). Association between disability status and dental attendance in Australia—A population-based study. *Community Dentistry and Oral Epidemiology* 49(33): 33-39. <https://doi.org/10.1111/cdoe.12571>

Snapshot of barriers to accessing oral healthcare in Australia	
Barriers experienced by people with disability	Barriers experienced by dentists and allied health staff
<ul style="list-style-type: none"> • Geographical and transport barriers • Cost of dental care and exclusion of dental from Medicare • Lack of dentists practicing in the public sector • Lack of dentists trained in Special Needs Dentistry • Negative attitudes and assumptions about disability within the oral healthcare sector • Lack of accessible, timely information about a person’s dental care needs and recommended procedures • Lack of access to supported decision making and opportunities for providing informed consent • Long wait times for appointments • Lack of ongoing, accessible information and education about preventative dental health • Lack of sedation options • Lack of knowledge and understanding among dental practitioners about communicating with people with disability, especially those who have complex communication support needs 	<ul style="list-style-type: none"> • Lack of opportunities for student dentists to upskill in SND at a tertiary level and beyond • Funding models that don’t support dentists to provide additional time and resources to people who may need it • Workforce shortages in metropolitan, but especially, regional, rural and remote areas • Lack of access to or upkeep of specialist equipment to treat people with complex needs • Lack of funding to support oral healthcare involvement in multidisciplinary interventions

Physical, social, economic, and emotional impacts

The physical cost of poor oral health is well established in research. People who experience poor oral health are at significant risk of experiencing localised problems such as:

- Decay and gum disease
- Bacterial infections
- A loss of teeth
- Inability to eat certain food or drinks
- Acute and chronic inflammation and pain

Anecdotal evidence from the lived experience of people our organisations represent, as well as academic research, suggest that it is common for people with disability—particularly people with an

intellectual disability—to end up receiving costly and complex dental interventions as a result of a lack of preventative dental healthcare or failure to provide alternative preventative procedures. These include people having teeth removed rather than fillings or not receiving functional replacements of extracted teeth.¹⁶

Poor oral health can also lead to serious issues and illnesses such as sepsis; compromised airway and swallowing issues; oral cancers; diabetes; lung conditions; adverse pregnancy outcomes; stroke; and cardiovascular disease.¹⁷

However, the consequences of poor oral health are multifactorial and impact people in many ways. As the Case Studies in this submission demonstrate, being shut out from dental care is also economically, emotionally and socially debilitating. These impacts may include:

- Issues with eating, sleeping or communicating comfortably
- Poor self-esteem associated with appearance
- Increased social isolation from one's community, including difficulties obtaining or sustaining employment, which puts people at risk of experiencing financial hardship—that risk being already greater for people with disability than that of the general population¹⁸
- Distress as a result of chronic pain and discomfort
- Trauma or other forms of distress from invasive dental procedures undertaken without adequate preparation, communication or informed consent
- Increased financial burden on people and their families.¹⁹

Some of these issues can lead to people experiencing behavioural changes or 'behaviours of concern',²⁰ particularly because of the trauma that a person may experience as a result of any of the above outcomes: especially invasive dental treatments, and especially where genuine consent has not been sought from the person.

'Behaviours of concern' can result in the use of restrictive practices in response to a behaviour of concern, often without the understanding of how that behaviour might be caused by untreated oral

¹⁶ Disability Oral Health Collective (DOHC), Your Dental Health Project team and Australasian Academy of Paediatric Dentistry (AAPD). 2020. Joint submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from: [Royal-Commission-Oral-Health-Disability-YDH-ASSCID-DOHC-20200210.pdf \(inclusionmelbourne.org.au\)](https://www.inclusionmelbourne.org.au/DOHC-20200210.pdf) p. 13.

¹⁷ Sievers K, Silk H, Quinonez R B and Clark M, (2010) (2014 version). The Relationship of Oral to Systemic Health, Smiles for Life: A National Oral Health Curriculum, STFM Group; Watanabe K. (2011). Periodontitis in Diabetics: Is Collaboration Between Physicians and Dentists Needed?, Dis Mon, 57(4): 206-213;

¹⁸ Sievers K, Silk H, Quinonez R B and Clark M, (2010) (2014 version). The Relationship of Oral to Systemic Health, Smiles for Life: A National Oral Health Curriculum, STFM Group.

¹⁹ Bascones-Martínez A, Arias-Herrera S, Criado-Cámara E, Bascones-Ilundáin J, Bascones-Ilundáin C. (2012). Periodontal disease and diabetes, Adv Exp Med Biol, 771:76-87.

²⁰ Behaviours of concern are defined by the NDIS Quality and Safeguard Commission as "behaviours of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit the use of, or result in, the person being denied access to ordinary community facilities." NDIS Quality and Safeguard Commission. 2019. Behaviour Support Questions & Answers. Retrieved from: www.ndiscommission.gov.au/sites/default/files/2022-02/behaviour-support-qas-august-2019.docx&usg=AOvVaw3h6AtDzU2BH_DSD07iyvZ6

pain or inflammation, or indeed trauma experienced as a result of a dental treatment. Restrictive practices can result in serious human rights breaches, and there is evidence that suggests people with an intellectual disability are at increased risk of experiencing restrictive practices.²¹

Oral health is often siloed in Australia's healthcare system and understood by practitioners as separate from a person's physical, emotional, social and interpersonal contexts. Yet oral health is a whole-of-life issue that must be understood holistically and, importantly, as a human rights issue.

Key legislative and policy settings

Our recommendations reflect the international legislative setting in relation to the provision of healthcare in Australia. **Article 25 of the UNCRPD** recognises the right to the highest attainable standard of health without discrimination on the basis of disability.

The right to health does not just mean the right to 'be healthy': it contains several important entitlements and freedoms, which include but are not limited to:

- Non-discrimination
- Control over your own health and body
- Free and informed consent
- Freedom from non-consensual medical treatment

Another important policy setting is the **National Roadmap for Improving the Health of People with Intellectual Disability** (the Roadmap),²² which is an Associated Plan to *Australia's Disability Strategy 2021-2031*.²³ The Roadmap aims to, among other things:

- Improve support for people with an intellectual disability and their families
- Develop better models of care for people with intellectual disability
- Provide support for health professionals to help them deliver quality care for people with an intellectual disability.

Healthy Mouths Healthy Lives: Australia's National Oral Health Plan 2015-2024 (the Plan)

acknowledges four priority populations: people who are socially disadvantaged or on low incomes; Aboriginal and Torres Strait Islander people; people living in regional and remote areas; and people with additional or specialised health care needs.²⁴

²¹ Clark, L.L., Hext, G. and Yyrichis, A. 2018. "Beyond restraint: raising awareness of restrictive practices in acute care settings", *International Journal of Nursing Studies*, Vol. 86, doi:10.1016/j.ijnurstu.2018.06.006

²² National Roadmap for Improving the Health of People with Intellectual Disability. 2021. Department of Health and Aged Care. Retrieved from: <https://www.health.gov.au/our-work/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability>

²³ Australia's Disability Strategy 2021-2031. Retrieved from: <https://www.disabilitygateway.gov.au/document/3106>

²⁴ Department of Health and Aged Care. Healthy Mouths Healthy Lives: Australia's National Oral Health Plan 2015-2024. Retrieved from: <https://www.health.gov.au/resources/publications/healthy-mouths-healthy-lives-australias-national-oral-health-plan-2015-2024?language=en>

Within those priority populations the Plan outlines several important strategies and goals that require action, including:

- Improved data collection
- Improved oral health literacy of carers and support workers of people with additional or specialised health care needs
- Building workforce capacity to effectively address the needs of people with additional or specialised health care needs
- Improve the physical access to dental treatment facilities

Finally, the adoption of the **World Health Organisation (WHO) Global Strategy on Oral Health in 2022** highlighted the need for signatory countries to address the persistent neglect of oral disease and conditions, and include oral health as part of universal healthcare coverage.

Being a member state of WHO, and given the exclusion of dental care from Medicare, Australia has a unique opportunity to demonstrate global leadership in this area. However, as academics have recently pointed out in the journal *Australian Health Review*, Australia is constrained by its lack of clinical leadership to guide federal government public policy on oral health.²⁵ They write:

“A paradigm shift is urgently needed to efficiently integrate oral healthcare within Medicare to improve oral health outcomes for all Australian citizens ... Leveraging the WHO’S Global Strategy on Oral Health, there arises the need to articulate important solutions through systems thinking, a focus on prevention and early intervention, and a population health approach beyond funding dental service provision.”²⁶

²⁵ Nguyen, T. M. et al. (2023). Corrigendum to: Is Australia’s lack of national clinical leadership hampering efforts with the oral health policy agenda? *Australian Health Review* 47(2), 192–196. doi:10.1071/AH22278

²⁶ Nguyen, T. M. et al. (2023). Corrigendum to: Is Australia’s lack of national clinical leadership hampering efforts with the oral health policy agenda? p. 195.

Literature review

Special Needs Dentistry (SND) has existed as a dental specialty since at least the 1970s,²⁷ with research in this area consistently demonstrating that individuals with disability have less regular dental attendance and are less likely to have their treatment needs met, resulting in poorer oral health outcomes at every stage of life.²⁸ However, despite increasing recognition of this disparity and growth of SND as a specialty in both Australia and internationally, the mechanism by which this occurs is not well understood, and so inequalities in oral health outcomes continue to persist.²⁹

Much of the available research literature is based on a medical model of disability, wherein disability is positioned as a problem to be solved.³⁰ This is in contrast to the social model of disability underlying the CRPD, which locates the “problem” not within the disability itself, but in the “disabling barriers” that result from society’s failure to adequately accommodate the needs of people with disability.³¹ This reliance on the medical model influences the research literature in a number of ways. Where research exists, it often relies on quantitative data, resulting in a lack of subjective, qualitative data that would enable the voices of people with disability, their families, and carers to be heard.³² Within this medicalised framework, individuals are grouped together under the banner of “disabled” and treated as objects, rather than individuals with diverse needs. This bias extends into dentistry practice, as many clinicians will see the disability rather than the patient and automatically exclude them from services.³³

The influence of the medical model of disability can also be seen in the way in which barriers to oral health care are conceptualised. When people with disability are automatically positioned as the problem, less attention is paid to environmental and social barriers that may impede access. In contrast, when barriers are examined through a social lens of disability, it becomes clear that barriers to access are multidimensional and vary from person to person.³⁴ The concept of “access” remains poorly defined

²⁷ Alumran, A, Almulhim, L, Almolhim, B, Bakodah, S, Aldossary, H & Alakrawi, Z (2018) Preparedness and willingness of dental care providers to treat patients with special needs, *Clinical, Cosmetic and Investigational Dentistry*, 231-236. DOI: 10.2147/CCIDE.S178114

²⁸ Lopez Silva CP, Singh A, Calache H, Derbi HA, Borromeo GL. Association between disability status and dental attendance in Australia—A population-based study. *Community Dent Oral Epidemiol.* 2021;49:33–39. <https://doi.org/10.1111/cdoe.12571>; Lim MAWT, Liberali SAC, Calache H, Parashos P, Borromeo GL. Perceived barriers encountered by oral health professionals in the Australian public dental system providing dental treatment to individuals with special needs. *Spec Care Dentist.* 2021;1–10. <https://doi.org/10.1111/scd.12581>

²⁹ Lim, M.A.W.T., Liberali, S.A.C. & Borromeo, G.L. Utilisation of dental services for people with special health care needs in Australia. *BMC Oral Health* 20, 360 (2020). <https://doi.org/10.1186/s12903-020-01354-6>

³⁰ Owens, J, Mistry, K, Dyer, TA (2011) Access to dental services for people with learning disabilities: Quality care?, *Journal of Disability and Oral Health* (2011) 12/1 17-27.

³¹ Oliver, M. (2013) ‘The Social Model of Disability: thirty years on,’ *Disability & Society*, 28(7): 1024.

³² Owens, J, Mistry, K, Dyer, TA (2011) Access to dental services for people with learning disabilities: Quality care?, *Journal of Disability and Oral Health* (2011) 12/1 17-27.

³³ Owens, J, Mistry, K, Dyer, TA (2011) Access to dental services for people with learning disabilities: Quality care?, *Journal of Disability and Oral Health* (2011) 12/1 17-27.

³⁴ Owens, J, Mistry, K, Dyer, TA (2011) Access to dental services for people with learning disabilities: Quality care?, *Journal of Disability and Oral Health* (2011) 12/1 17-27.

in the literature, with the majority of studies defining access solely on the basis of service utilisation; again, reflecting the influence of the medical model with minimal attention paid to the social aspect of access to oral health care.³⁵ This lack of a clear definition can become problematic when policymakers attempting oral health care reform assign different meanings to the term.³⁶ In reviewing the research literature, it unfortunately becomes clear that the social model of disability is not the norm within dentistry; a reality reflected in the attitudes of clinicians towards patients with disability, the lack of interdisciplinary collaboration with other health services, and the failure to acknowledge the rights of people with disability, all of which present significant barriers to accessing oral health care.

The research literature also reflects the historical division that exists between general health care and oral health care.³⁷ This lack of interdisciplinary interaction can be traced back to the notion that “the mouth is separate from the rest of the body”.³⁸ The disciplines of medicine and dentistry evolved separately, each with their own distinct education systems, clinical networks, and funding arrangements.³⁹ This siloisation continues to this day and is a global concern, despite advocacy by the World Health Organisation (WHO) beginning in 2007 for dental care to be integrated into primary health care.⁴⁰ One consequence of this failure to integrate is the tendency of health care systems to prioritise other medical issues over oral health, resulting in potentially preventable conditions being missed and escalating into far more serious conditions, causing both undue suffering to the patient and ultimately presenting a greater burden to the health care system.⁴¹ The division is further perpetuated by funding arrangements and models of care that continue to exclude oral health care from general primary health care.⁴² Where integration between the two systems has been successful, studies indicate that a key

³⁵ Naseem M, Shah AH, Khiyani MF, Khurshid Z, Zafar MS, Gulzar S, AlJameel AH, Khalil HS. Access to oral health care services among adults with learning disabilities: a scoping review. *Ann Stomatol (Roma)*. 2017 Jan 10;7(3):52-59. doi: 10.11138/ads/2016.7.3.052. PMID: 28149451; PMCID: PMC5231790.

³⁶ Naseem M, Shah AH, Khiyani MF, Khurshid Z, Zafar MS, Gulzar S, AlJameel AH, Khalil HS. Access to oral health care services among adults with learning disabilities: a scoping review. *Ann Stomatol (Roma)*. 2017 Jan 10;7(3):52-59. doi: 10.11138/ads/2016.7.3.052. PMID: 28149451; PMCID: PMC5231790.

³⁷ Lim MAWT, Liberali SAC, Calache H, Parashos P, Borromeo GL. Perceived barriers encountered by oral health professionals in the Australian public dental system providing dental treatment to individuals with special needs. *Spec Care Dentist*. 2021;1–10. <https://doi.org/10.1111/scd.12581>; Sen Gupta T, Stuart J. Medicine and dentistry: Shall ever the twain meet? *Aust J Gen Pract*. 2020 Sep;49(9):544-548. doi: 10.31128/AJGP-06-20-5482. PMID: 32864667.

³⁸ Lim MAWT, Liberali SAC, Calache H, Parashos P, Borromeo GL. Perceived barriers encountered by oral health professionals in the Australian public dental system providing dental treatment to individuals with special needs. *Spec Care Dentist*. 2021;1–10. <https://doi.org/10.1111/scd.12581>

³⁹ Sen Gupta T, Stuart J. Medicine and dentistry: Shall ever the twain meet? *Aust J Gen Pract*. 2020 Sep;49(9):544-548. doi: 10.31128/AJGP-06-20-5482. PMID: 32864667.

⁴⁰ Petersen PE. World Health Organization global policy for improvement of oral health – World health assembly 2007. *Int Dent J* 2008;58(3):115–21. doi: 10.1111/j.1875-595x.2008.tb00185.x.

⁴¹ Prasad M, Manjunath C, Murthy AK, Sampath A, Jaiswal S, Mohapatra A. Integration of oral health into primary health care: A systematic review. *J Family Med Prim Care* 2019;8:1838-45; Lim MAWT, Liberali SAC, Calache H, Parashos P, Borromeo GL (2022) Mentoring of oral health professionals is crucial to improving access to care for people with special needs. *PLoS ONE* 17(4): e0266879. <https://doi.org/10.1371/journal.pone.0266879>

⁴² Sen Gupta T, Stuart J. Medicine and dentistry: Shall ever the twain meet? *Aust J Gen Pract*. 2020 Sep;49(9):544-548. doi: 10.31128/AJGP-06-20-5482. PMID: 32864667.

enabling factor is interprofessional collaboration.⁴³ It has been suggested that the first step in overcoming this divide should be to incorporate integrated models of care at the undergraduate and postgraduate levels for both medical and dental students.⁴⁴

The majority of research into SND has been limited in focus, primarily examining rates of utilisation, oral health outcomes among people with disability, and barriers to accessing oral health care.⁴⁵ The need for further research has been identified in a number of areas, including:

- How to improve the confidence and willingness of clinicians to work with people with disability.⁴⁶
- Evaluation of initiatives to identify what works and further establish best practice.⁴⁷
- Reducing barriers and improving access through a social model of disability lens.⁴⁸
- How to better reach and educate informal carers on oral health care.⁴⁹

Although there is still a great need for further research, from the existing literature, it is possible to identify some elements of best practice. These include:

- Integration of oral health care into primary health care.
- Collaboration between community dental clinicians and SND specialists.
- Reduced reliance on specialist services.
- Increased focus on preventative care.
- Education and training of carers/
- Promoting SND in both medical and dental curricula.

At the end of this submission, several examples of initiatives incorporating these elements of best practice will be explored.

⁴³ Prasad M, Manjunath C, Murthy AK, Sampath A, Jaiswal S, Mohapatra A. Integration of oral health into primary health care: A systematic review. *J Family Med Prim Care* 2019;8:1838-45; Kaufman LB, Henshaw MM, Brown BP, Calabrese JM. Oral health and interprofessional collaborative practice: Examples of the team approach to geriatric care. *Dent Clin North Am* 2016;60:879-90; Atchison KA, Weintraub JA. Integrating oral health and primary care in the changing health care landscape. *N C Med J* 2017;78:406-9.

⁴⁴ Prasad M, Manjunath C, Murthy AK, Sampath A, Jaiswal S, Mohapatra A. Integration of oral health into primary health care: A systematic review. *J Family Med Prim Care* 2019;8:1838-45.

⁴⁵ Owens, J, Mistry, K, Dyer, TA (2011) Access to dental services for people with learning disabilities: Quality care?, *Journal of Disability and Oral Health* (2011) 12/1 17-27.

⁴⁶ Lim MAWT, Liberali SAC, Calache H, Parashos P, Borromeo GL (2022) Mentoring of oral health professionals is crucial to improving access to care for people with special needs. *PLoS ONE* 17(4): e0266879.

<https://doi.org/10.1371/journal.pone.0266879>

⁴⁷ Lim MAWT, Liberali SAC, Calache H, Parashos P, Borromeo GL (2022) Mentoring of oral health professionals is crucial to improving access to care for people with special needs. *PLoS ONE* 17(4): e0266879.

<https://doi.org/10.1371/journal.pone.0266879>

⁴⁸ Naseem M, Shah AH, Khiyani MF, Khurshid Z, Zafar MS, Gulzar S, AlJameel AH, Khalil HS. Access to oral health care services among adults with learning disabilities: a scoping review. *Ann Stomatol (Roma)*. 2017 Jan 10;7(3):52-59. doi: 10.11138/ads/2016.7.3.052. PMID: 28149451; PMCID: PMC5231790.

⁴⁹ Wilson, N.J.; Patterson-Norrie, T.; Bedford, C.; Bergstedt, N.; Mendoza, L.M.; Villarosa, A.R.; George, A.; Karve, A. Evaluation of Smiles for Life: A Caregiver Focused Oral Health Education Programme. *Disabilities* 2022, 2, 564–574. <https://doi.org/10.3390/disabilities2040040>

Key issues

There are four main interlinked issues that generate many of the barriers people with disability experience, and which inhibit people from receiving safe, accessible and equitable dental care.

In some cases, these issues present **human rights breaches**: this is demonstrated by the stories shared by people with disability and family members that appear throughout this section, as well as in the Case Studies section of this submission.

The associated recommendations therefore aim to initiate actionable steps to ameliorate these issues so that Australia can more meaningfully meet its obligations under Article 25 of the UNCRPD.

1. Data collection on the oral health of people with disability is inadequate

There is a lack of national data on the oral health needs of people with disability, and particularly people with an intellectual disability.

Although the Australian government conducts the National Child Oral Health Study and the National Survey of Adult Oral Health every 10 years, these surveys do not capture the baseline oral health status of people with disability.

There is also a lack of data differentiating oral health needs and experiences by disability type. Other important intersections within this—such as gender or Aboriginal and Torres Strait Islander status—are not collected.

This lack of data, along with a proven methodology that is safe and accessible to people with disability with which to collect it, presents a major barrier to understanding and ameliorating the experiences and oral health needs of people with disability.

While there is an increasing academic literature that demonstrates the oral health needs of people with disability, as well as the barriers to accessing dental services, this research is sparse and the pathways that result in poorer oral health outcomes are not well understood.⁵⁰

⁵⁰ Lopez Silva, C. P., Singh, A., Calache, H., Derby, H. A., and Borromeo, G. L. (2021). Association between disability status and dental attendance in Australia—A population-based study. *Community Dentistry and Oral Epidemiology* 49(33): 33-39. <https://doi.org/10.1111/cdoe.12571>

Recommendations

1. Improve data collection on the oral health of people with disability

This was listed as a goal in *Healthy Mouths Healthy Lives: Australia's National Oral Health Plan 2015-2024* in relation to the priority population of people with additional or specialised needs, which aimed to “collect national baseline and ongoing data to more accurately identify the numbers of people with specialised health care needs, their oral health status and treatment needs.”⁵¹

However, it is not clear that this has occurred.

We strongly recommend this goal be actioned, particularly given the work being done by the Department of Social Services to pilot and develop a National Disability Data Asset (NDDA). Oral health data, including qualitative data through the lived experience of people with disability, is critical information that should be included within any data linkages project like the NDDA.

As a starting point for Government, we recommend making alterations to the National Child Oral Health Study and the National Survey of Adult Oral Health to include specific data collection on children and adults with disability. Data must also capture disability type, as well as other intersections such as Cultural and Linguistically Diverse (CALD) or Aboriginal and Torres Strait Islander people with disability.

2. Dental care is unaffordable

Because dental care is not covered by Medicare, and approximately 86% of the dental health workforce practices in the private sector, cost is a major barrier for people with disability in accessing dental care, particularly as a preventative health measure.

There is an abundance of evidence demonstrating that socioeconomic factors have a direct role in influencing oral health. This is known as the ‘social gradient of health’,⁵² which shows that people with a lower socioeconomic status tend to experience higher rates of disease and relatively poorer health overall than people with a higher socioeconomic status.

⁵¹ Department of Health and Aged Care. *Healthy Mouths Healthy Lives: Australia's National Oral Health Plan 2015-2024*. Retrieved from: <https://www.health.gov.au/resources/publications/healthy-mouths-healthy-lives-australias-national-oral-health-plan-2015-2024?language=en>

⁵² Australian Institute of Health and Welfare. *The geography of disability and economic disadvantage in Australian capital cities*. Catalogue no.DIS 54. 2009. Retrieved from: <https://www.aihw.gov.au/reports/disability/disability-economic-disadvantage-capital-cities/contents/table-of-contents>;

Commission on Social Determinants of Health. *Closing the gap in a generation: health equity through action on the social determinants of health*. Final report of the Commission on Social Determinants of Health. Geneva: World Health Organization; 2008.;

Liu, N., Kruger, E., and Tennant M. 2021. Identifying the gaps in public dental services locations for people living with a disability in metropolitan Australia: a geographic information system (GIS)-based approach. *Australian Health Review* 45, p. 178-184. <https://doi.org/10.1071/AH19252>

People with a lower socioeconomic status rely primarily on the government-funded public sector for their dental care.⁵³

This is because people with disability face higher cost of living pressures than people without disability and are more likely to have a lower level of personal income.⁵⁴ People with disability also experience higher rates of poverty than those without disability.⁵⁵

The National Centre for Social and Economic Modelling (NATSEM) has estimated the extra costs of living for households with a member with disability compared with households with similar characteristics but with no member with disability.⁵⁶ They found that:

- Households with an adult with profound or severe disability need an extra \$173 per week on average over and above their 2015-16 net income, and
- Households with an adult with mild or moderate disability need an extra \$87 per week on average.

More recent data published by the Centre for Research Excellence in Disability and Health showed that 34% of people with disability (1,154,917 people) report living in financial hardship compared to 14% of people without disability.

In addition, a 2022 report by the AIHW reported that while people with disability are as likely as people without disability to have an income, that income is far more likely to come primarily from a government payment than from salary or wages.⁵⁷

Among people with disability, people with an intellectual disability are among the least likely to receive an income from a wage or salary through employment: 72% of people with an intellectual disability's main source of income comes from a government pension or allowance. For most people, it's the Disability Support Pension (DSP), which at \$468 per week, means most people with an intellectual disability live close to the poverty line: which is \$414.98 per week.⁵⁸

⁵³ Donaldson, A.N., Everitt, B., Newton, T., Steele, J., Sherriff, M., and Bower, E. 2008. The effects of social class and dental attendance on oral health. *Journal of Dental Research* 87(1):60-64.

⁵⁴ Australian Institute of Health and Welfare. (2022). *People with disability in Australia*. Retrieved from <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia>

⁵⁵ According to a report published by UNSW and the Australian Council of Social Service, 1 in 6 people with disability were living in poverty, compared with just 1 in 10 Australians without disability. See: Davidson, P., Saunders, P., Bradbury, B. and Wong, M. (2018), [Poverty in Australia 2018](#). ACOSS/UNSW Poverty and Inequality Partnership Report No. 2, Sydney: ACOSS.

⁵⁶ Li, J., Brown, L., La. H.N., Miranti, R., and Vidyattama, Y. (2019). *Inequalities in Standards of Living: Evidence for Improved Income Support for People with Disability*. NATSEM, Institute for Governance and Policy Analysis, University of Canberra. Report commissioned by the Australia Federation of Disability Organisations. September 2019.

⁵⁷ 43% or 780,000 people with disability aged 15-64 receive an income that comes primarily from government support rather than from salary or wages, compared with 7.9% or 999,000 people without disability. See: Australian Institute of Health and Welfare. (2022). *People with disability in Australia*. Retrieved from <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia>

⁵⁸ Melbourne Institute for Applied Economic and Social Research (2022). *Poverty Lines: Australia*. Retrieved from: [Poverty-Lines-Australia-June-2022.pdf \(unimelb.edu.au\)](#)

This means Australians with disability are very likely to have low socioeconomic status and, as such, are more likely to experience cost as a major barrier to accessing dental care.

This is also reflected in current data. The AIHW, for example, suggests that around 1 in 4 people (27.5% or 449,400 people) aged under 65 with disability living in households who needed to see a dental professional in the last 12 months delayed seeing or did not see a dental professional because of cost.

This rate is highest among females (30%), those aged 25-65 (34%), those living in outer regional and remote areas (30%) and those with a head injury, stroke or acquired brain injury (34%).

For people with disability who live in regional, remote or rural areas, there is an added cost burden associated with travel costs to get to a dentist. Given the severe shortage of dentists who specialise in Special Needs Dentistry, travel costs may also impact people who live in metropolitan areas.

Further, Domiciliary dental care (DDC) is a model that provides oral healthcare within a person's place of residence. This is offered in many states in Australia but is usually only partially subsidised for those who hold a Health care or Pensioner concession card.

There is a growing number of public and private DDC services operating in Australia today. Historically, this model has mainly been provided for older Australians, particularly those residing in an Aged Care facility.⁵⁹ There is evidence that demonstrates the DDS model improves access to dental care for older members of the community.

As such, DDC is an important modality to consider for improving access to dental care for people of all ages with disability who may find it difficult to attend a dental clinic,⁶⁰ whether due to geographical reasons; for those who do not have sufficient supports to travel to a dental clinic; those who have anxieties or even trauma associated with dental clinics; or those who have sensory support needs that cannot be suitably supported in a dental clinic.

⁵⁹ Lim, M.A.W.T., Liberali, S.A.C. & Borromeo, G.L. Utilisation of dental services for people with special health care needs in Australia. *BMC Oral Health* **20**, 360 (2020). <https://doi.org/10.1186/s12903-020-01354-6>.

⁶⁰ Lim, M.A.W.T., Liberali, S.A.C. & Borromeo, G.L. Utilisation of dental services for people with special health care needs in Australia. *BMC Oral Health* **20**, 360 (2020). <https://doi.org/10.1186/s12903-020-01354-6>.

Recommendations

2. Include dental care as part of Medicare for Australians with disability

Preventative dental treatment, plus a number of common dental procedures, must be added to Medicare for people with disability to considerably reduce or eliminate the cost of seeing a dentist. Disability may be inclusive of, but not limited to, neurodivergence, mental illness, intellectual disability, chronic illness, sensory disability and physical disability.

Australia's Healthy Mouths Health Lives: National Oral Health Plan 2015-2024 flagged the expansion of the Child Dental Benefits Schedule (CDBS) to incorporate adults within the Plan's 'priority populations', which included people who are socially disadvantaged and people with additional or specialised health care needs. We recommend this measure be adopted as a matter of urgency, especially since there is evidence to suggest that the CDBS did result in an increased access to dental services and improved visiting patterns in low-income households.⁶¹

Over time, work must be done to develop relevant economic modelling and planning to devise a path forward to enable the full inclusion of dental as part of Medicare for people with disability, as well as other priority groups identified in the *National Oral Health Plan 2015-2024*.

3. Sustainably invest in Domiciliary dental care (DDC)

DDC should be sustainably funded across Australia, with a focus on regional, rural and remote areas, to allow people to receive subsidised dental treatment at home to ameliorate the costs and administrative burden of travelling long distances to see a dentist.

⁶¹ Stormon, N., Do, L., & Sexton, C. (2022). Has the Child Dental Benefits Schedule improved access to dental care for Australian children? *Health & Social Care in the Community*, 30. <https://doi.org/10.1111/hsc.13803>

3. There is a shortage of dentists practicing in the public sector, plus an overall shortage of dentists with skills in Special Needs Dentistry (SND)

In Australia, approximately 86% of the dental health workforce practices in the private sector. This equates to roughly 80% of all dental care provided by the private sector on a fee-for-service basis, leaving the remaining 20% relying on government-funded services in the public sector.⁶²

This means there is an inherent maldistribution of workforce in Australia's dental care system.

This is true both in terms of the uneven split between the public and private sectors, but also geographically: most dentists are employed in capital cities (79.9% of all employed dentists), while approximately 0.9% are employed in remote or very remote areas.⁶³

As described on earlier in this submission, many people with disability cannot access dental care because it is not affordable. Most people with disability rely on the public system to access dental care. However, for some—such as low-income earners without concession cards—even the public sector is inaccessible due to cost.

There is a significant demand among people with disability for dental services in the public sector. This results in long wait times, which can be a major disincentive for people to regularly attend dental appointments—especially when people with disability may face additional barriers relating to transport.⁶⁴ This inhibits people from receiving critical preventative oral healthcare, which would decrease the likelihood of invasive interventions such as extraction. As the Case Studies in the following section show, invasive procedures are a common and horrific experience for people with disability, especially people with an intellectual disability.

Data from the AIHW shows that around 1 in 8 (12.5% or 201,500) people aged under 65 with disability living in households who needed to see a dental professional in the last 12 months have been on a public waiting list for dental care. This rate is highest among those with severe or profound disability (19.5% or 91,900), those with head injury, stroke or acquired brain injury (21.5% or 23,600), and those living in outer regional and remote areas (14.7% or 22,000).⁶⁵

⁶² Australian Institute of Health and Welfare. (2020). Oral health and dental care in Australia. Retrieved from: <https://www.aihw.gov.au/reports/dental-oral-health/oral-health-and-dental-care-in-australia/contents/dental-workforce>

⁶³ Health Workforce Australia: Australia's Future Health Workforce: Oral Health – Overview. 2014. Retrieved from: <https://www.health.gov.au/resources/publications/oral-health-australias-future-health-workforce-reports?language=en>

⁶⁴ da Rosa, S. V., Moysés, S. J., Theis, L. C., Soares, R. C., Moysés, S. T., Werneck, R. I., & Rocha, J. S. 2020. Barriers in Access to Dental Services Hindering the Treatment of People with Disabilities: A Systematic Review. *International journal of dentistry*, 2020, 9074618. <https://doi.org/10.1155/2020/9074618>

⁶⁵ Australian Institute of Health and Welfare. 2023. *Oral health and dental care in Australia*. Retrieved from: <https://www.aihw.gov.au/reports/dental-oral-health/oral-health-and-dental-care-in-australia>

Around 3 in 10 (30% or 61,000) people aged under 65 with disability living in households who had been on a public dental waiting list in the last 12 months have not received dental care.⁶⁶

Special Needs Dentistry (SND) is one the newest Australian dental disciplines with the aim of providing better treatment to people with complex oral health needs. Australia and New Zealand were two of the first countries in the world to establish SND as a discipline.

SND's scope is broad. It is "dentistry that supports the oral health care needs of people with an intellectual disability, medical, physical or psychiatric conditions that require special methods or techniques to prevent or treat oral health problems, or where such conditions necessitate special dental treatment plans".⁶⁷

However, as Dr Avanti Karve—President Elect of the Australia and New Zealand Academy of Special Needs Dentistry (ANZASND)—points out,

"Not all patients with special health needs need specialist care. Many can access care in the community if 'reasonable adjustments' are made to ensure equity of access to care. We need more interest from general dental practitioners ... so specialist practice is reserved for the most complex and medically unwell".⁶⁸

However, due to the barriers people face in accessing general dental care settings—including a general reluctance among many oral health professionals to treat people with disability, of which there is much evidence⁶⁹—there is a significant and unsustainable demand for dentists who specialise in SND. This results in massive wait times for people who often need urgent care.

⁶⁶ Australian Institute of Health and Welfare. (2020). Oral health and dental care in Australia. Retrieved from: <https://www.aihw.gov.au/reports/dental-oral-health/oral-health-and-dental-care-in-australia/contents/dental-workforce>

⁶⁷ Australian Dental Association. April 2022. "Special Needs Dentistry spotlight (part 1)". Retrieved from: [https://www.ada.org.au/News-Media/News-and-Release/Latest-News/Special-needs-dentistry-spotlight-\(part-1\)-1504202](https://www.ada.org.au/News-Media/News-and-Release/Latest-News/Special-needs-dentistry-spotlight-(part-1)-1504202)

⁶⁸ Australian Dental Association. April 2022. "Special Needs Dentistry spotlight (part 1)". Retrieved from: [https://www.ada.org.au/News-Media/News-and-Release/Latest-News/Special-needs-dentistry-spotlight-\(part-1\)-1504202](https://www.ada.org.au/News-Media/News-and-Release/Latest-News/Special-needs-dentistry-spotlight-(part-1)-1504202)

⁶⁹ Pradhan A, Spencer A, Slade G. Factors influencing oral health of adults with physical and intellectual disabilities in various living arrangements. *Aust Dental J.* 2007;52(S4):S30–1;
Pradhan A, Slade GD, Spencer AJ. Factors influencing caries experience among adults with physical and intellectual disabilities. *Commun Dent Oral Epidemiol.* 2009a;37(2):143–54;
Pradhan A, Slade GD, Spencer AJ. Access to dental care among adults with physical and intellectual disabilities: residence factors. *Aust Dent J.* 2009b;54(3):204–11.

B is a young person with an intellectual disability.

I'm on a waiting list to get an appointment right now but I'm not sure how long it will take. The dentist I go to is a government service.

When it came to get my wisdom teeth out I had to wait 2 years. I was in so much pain, I was getting headaches.

When I need to go for a check-up I usually have to wait a month for an appointment.

There are currently less than 25 Special Needs Dentists practicing in Australia.

Those dentists reside in some, but not all, capital cities.

There are also barriers that disincentivise dentistry students from upskilling in SND, including the cost of studying, which at some University Specialist SND Training programs is upwards of \$130 000, and places are not offered with scholarships. Further, career pathways and financial incentives in this field can be unreliable.⁷⁰

Despite it being a requirement of the Australian Dental Council of Australia (ADC), not all universities include SND in their curriculum. In those that do, programs vary widely. University SND programs are impacted by budget constraints, and not all universities have a designated staff member available who has a background in SND.

This gap in tertiary curriculums is a widespread issue. We know, for example, that training and education on the overall health of people with an intellectual disability in university medical and nursing schools is very low, containing:

- A median of 2.6 hours' compulsory content across 12 medical schools
- No intellectual disability content in 52 percent of nursing schools and very limited content overall.⁷¹

⁷⁰ Disability Oral Health Collective (DOHC), Your Dental Health Project team and Australasian Academy of Paediatric Dentistry (AAPD). 2020. Joint submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from: [Royal-Commission-Oral-Health-Disability-YDH-ASSCID-DOHC-20200210.pdf \(inclusionmelbourne.org.au\)](https://www.inclusionmelbourne.org.au/DOHC-20200210.pdf)

⁷¹ Trollor, J., et al. (2016). Intellectual disability health content within medical curriculum: an audit of what our future doctors are taught. *BMC Medical Education* 16 (105):

Recommendations

4. Sustainably invest in Special Needs Dentistry (SND) and upskill general dentists to treat people with disability

This can be achieved by including measures in Australia's next 10-year National Oral Health Plan to promote the systematic upskilling of dentists in treating people with a disability and generally invest in SND practices at a tertiary level.

While there is a severe shortage of dentists trained in SND, we emphasise in this submission that many people with disability—including many people with complex needs—can access care in the community through general dental practices if reasonable adjustments are made to ensure equity of access to care. We acknowledge that SND is a critical discipline that should be invested in and promoted, and that it should be reserved for those with the most complex support needs.

A reasonable adjustment refers to any form of support, assistance or adjustment to practice that is necessary, possible and reasonable to eliminate the barriers that inhibit people with disability from getting the dental care they need. We highlight several examples of what this might look like for different people in this submission. We also note that the requirement to make reasonable adjustments is implicit in the requirement to avoid indirect discrimination against a person with disability under section 6 of the *Disability Discrimination Act 1992*.

The upskilling of dentists to treat people with disability was not included in sufficient detail in the current *National Oral Health Plan 2015-2024*. This should be added as a matter of urgency, and actualised through collaboration between Government, the dental healthcare sector, and the disability support sector.

The disability support sector, in this instance, refers to Disability Representative Organisations, NDIS and non-NDIS service providers, self-advocacy organisations, and advocacy organisations across states and territories. We also recommend working with the Department of Health and Aged Care team responsible for the Curriculum development in the health of people with an intellectual disability.

University fee subsidies or other incentives should also be promoted to encourage more students to undertake training in SND, given that there are less than 25 practicing dentists in Australia with training in SND.

In addition, the small number of dentists with skills in SND means there is a lack of opportunity for education and information sharing between the SND community and general dentistry, as well as other critical and overlapping parts of the health sector like general medicine, psychology, other allied health services, as well as the disability support sector.

A more robust partnership between SND, general dentistry and the disability support sector is particularly important. The promotion of SND and increasing the number of dentists skilled in SND may help actualise this.

The *Your Dental Health* project by Inclusion Melbourne and a range of dental health professionals, disability support professionals and people with an intellectual disability found that there are several critical knowledge gaps within the dental care sector about the disability support sector, which exacerbate the barriers faced by people with disability:

- The difference between supported decision making and substitute decision making, as well as relevant Guardianship laws in different jurisdictions
- The difference between informal supports (such as family) and support workers
- Positive Behaviour Support, Behaviour Support Plans and restrictive practices
- Individual planning documents that may be helpful in supporting dentists to support the needs of people with disability
- Assistive and Augmentative Communication (AAC), as well as individual communication needs in general.⁷²

As such, any upskilling of dentists in SND must also include collaboration with the disability support sector—including, especially, collaboration with people with disability in understanding how best to support the oral health needs of people with disability.

Recommendation

5. Promote interprofessional education and practice between Special Needs Dentistry (SND), general dental practitioners, general medicine, the disability support sector, and people with disability themselves to increase the capacity of general dentists to treat people with disability

Dental care is too often siloed from general healthcare. The upskilling of dentists must also involve collaboration with health professionals across the health sector as a critical pathway to achieving greater interdisciplinary communication and promotion of awareness of the oral, and general, health needs of people with disability.

Importantly, this must also happen in collaboration with the disability support sector (as defined in recommendation 4), and in particular, in collaboration with people with disability, who are of course the experts in their own lives. As described in this submission, the National Roadmap for Improving the Health of People with Intellectual Disability highlights this need and provides an opportunity for systemic change.

This enhanced collaboration should support the embedding of vital human rights-based provisions to dental care outlined in other recommendations, including the promotion of knowledge and practice models of Supported Decision Making and Positive Behaviour Support as part of oral health care, as per recommendation 10.

⁷² Inclusion Melbourne. *Your Dental Health*. Retrieved from: <https://inclusionmelbourne.org.au/projects/your-dental-health/>

4. Dental services are not responsive to the support needs of people with disability

The support needs of people with disability when it comes to oral care vary greatly. At times, those needs may be complex for a variety of reasons. However, it is vital to be aware that people with disability often have greater support needs **not because of their disability** specifically: the experience of disability is defined largely by social exclusion, disadvantage caused by socioeconomic factors, negative community attitudes and assumptions, and a lack of rights-based support that is responsive to peoples' needs.

As much as diagnosis can be important in oral care in relation to comorbidities in oral health, or where certain conditions or medications may predispose people to a greater risk of poor oral health, it must be recognised that the barriers people experience to accessing dental care that is responsive to their support needs are caused by social, cultural and economic factors and not by a person's disability.

B is a young person with an intellectual disability.

People need to change locations to get x-rays—can't it all happen in the same place? Sometimes I end up having to go to the hospital and spend 2 hours waiting just to get some x-rays.

They should have dentists on the ground floor and make sure there's enough parking for people. Sometimes dentists aren't very accessible for people who use a wheelchair.

Recommendations

6. Sustainably fund rights-based training for dentists and allied health professionals that is co-designed and co-led by people with disability and family members to promote understandings of disability grounded in lived experience and inclusive practice

The current National Safety and Quality Health Services (NSQHS) Guide for Dental Practices and Services (the Guide) contains several significant gaps when it comes to setting a standard of quality and safety in healthcare for people with disability.

We strongly recommend revising the NSQHS Guide to include measures that promote rights-based, inclusive practice grounded in the lived experience of people with disability. This should be a basic standard of care that will guide all dental practitioners across Australia in their interactions and treatment of people with disability to ensure that all people receive care that upholds their human rights and dignity.

In addition, our organisations hear time and again that there is a lack of adequate sedation pathways offered to people with disability as a way to minimise distress or anxiety around health procedures, as well as a way of providing more equitable and inclusive access to dental care.

While there are a range of reasonable adjustments that could be put in place to avoid the need for sedation—for example, low-sensory waiting and treatment rooms or social stories provided in clinics—there are some people with disability who require support through sedation.

This does not automatically mean the use of General Anesthesia (GA). Although necessary for some, other less intrusive options must be available.

All these options must be presented to a person and their supports in a way that makes sense to them, enabling the person to make their own decisions about, and informed consent to, the use of whichever sedation technique. Decision-making and informed consent are discussed in more detail later in this section.

Recommendation

7. Improve access to a range of sedation pathways and provide better support for people who may require sedation, with the use of General Anesthesia (GA) reserved as a last resort

While there are a range of reasonable adjustments that could be put in place to avoid the need for sedation, many people with disability—particularly for people with an intellectual disability or people with complex support needs—require support through use of sedation to minimise distress or anxiety around health procedures, as well as provide more equitable access to dental care. People with disability may need a different sedation approach to others, and access to a range of sedation pathways must be provided.

This does not automatically mean the use of General Anesthesia (GA). While GA may be necessary for some, other less intrusive forms of sedation must be available and all options presented to a person and their supporters in a way that makes sense to them, enabling the person to make their own decisions about, and provide informed consent to, the sedation approach to the maximum extent possible.

Communication and information sharing

People with disability, and particularly people with an intellectual disability, have told us that dentists tend not to communicate well with people with disability: that is, communicating in a way that makes sense to the person and respects their right under Article 25 of the UNCRPD to have control over their own health and body; have free and informed consent; and freedom from non-consensual medical treatment.

B is a woman with Down syndrome.

There isn't enough accessible information about what procedures will happen. People with an intellectual disability need time to go away, go through the information with a family member or other supporter, and take the time to understand what will happen during the appointment.

You get put under pressure to make a decision and don't get any time to think about what you need and whether you want to do it.

Sometimes I had appointments where I wasn't told what was going to happen and how much pain would happen. Even how long my mouth would be open for and how long I would be numb for.

Once I had to have a root canal and I was numb for 2 days. No one told me, and when I rang the dentist no one could give me any information about what was happening. I couldn't work and it was so uncomfortable.

I also think dentists don't listen well. Once I tried to tell the dentist I was in pain in the middle of a root canal and they said "no you're not".

Dentists must give people Easy Read information so they can understand what is going to happen and make a decision in a way that makes sense to them. And people need enough time to do that.

There needs to be better communication and respect for people with disability from dentists.

Research shows that when communication between dental practitioners and people with disability is not responsive to the person's communication needs, people with disability are at greater risk of over-treatment, under-treatment, non-consensual treatment, delays in management of oral health issues and other forms of unsafe or poor-quality care.⁷³

When communication does not happen in a way that respects the person and makes sense to them, people have negative experiences and form negative associations with dental care. It disincentivises people from getting the healthcare they may need and does not respect peoples' human rights.

One important way to make sure communication happens in a way that respects peoples' human rights and enables genuine informed consent to be provided from the person about their health and body—as well as creating a positive experience for all—is by, as B pointed out above:

1. Providing people with Easy Read information about any and all aspects of their care and treatment options, risks and benefits.
2. Giving people enough time to process the information and, if needed, to work through the information with a trusted supporter.

⁷³ Disability Oral Health Collective (DOHC), Your Dental Health Project team and Australasian Academy of Paediatric Dentistry (AAPD). 2020. Joint submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Retrieved from: [Royal-Commission-Oral-Health-Disability-YDH-ASSCID-DOHC-20200210.pdf \(inclusionmelbourne.org.au\)](https://www.inclusionmelbourne.org.au/DOHC-20200210.pdf)

R is a person with an intellectual disability.

I had a tooth that was decaying and immediately they said they wanted to take it out. The dentist didn't take into account my struggles with pain and the other things I needed, like a support person.

They didn't listen to me, just said they needed to 'get this out ASAP'. I felt shook up and dizzy just from the needle that had to go in.

I wanted them to allow me a support person to be with me in the room so they can help me communicate my support needs and any issues I have.

I don't want that to happen to anyone else.

Some people may not communicate in ways most dental practitioners are used to. They may use Assistive or Augmentative Communication (AAC) or other forms of communication. They may rely on a support worker to assist in their communication. It is vital that these tools be respected and made available to the person throughout every step of their care.

Communication can also be enhanced between dental practitioners and people with disability through informal and formal supports that the person may receive support from. Creating collaborative pathways between dental practitioners, people with disability and their support systems is a vital and achievable way of making communication more inclusive and rights-based.

This kind of pathway is described in detail in the *Oral Health and Intellectual Disability* guide for practitioners, which was produced as part of the *Your Dental Health* project by Inclusion Melbourne.⁷⁴

Recommendations

8. Provide communication and information in a way that makes sense to the person

Make an addition to the National Safety and Quality Health Services (NSQHS) Guide for Dental Practices and Services that outlines the need to support all peoples' unique communication styles, including by making Easy Read information available to the person, together with sufficient time to work through the information with whatever supports the person needs.

Providing communication and information in a way that makes sense to the person is also intimately connected to, and flows from, a way of thinking and relating that is grounded in respect and a commitment to upholding the human rights of people with disability, reflecting the UNCRPD to which Australia is bound.

⁷⁴ Inclusion Melbourne. Your Dental Health. Retrieved from: <https://inclusionmelbourne.org.au/projects/your-dental-health/>

9. Ensure use of Assistive or Augmentative Communication (AAC) tools are respected and provided where a person uses them

Make an addition to the National Safety and Quality Health Services (NSQHS) Guide for Dental Practices and Services that outlines the need to support all peoples' unique communication styles, including by respecting peoples' use of AAC tools and ensuring these are made available to people wherever and whenever necessary.

Attitudes, Consent and Supported Decision Making

Respectful and inclusive communication and information is a basic requirement for genuine informed consent to be provided by anyone receiving any kind of healthcare. It should be a basic expectation of all dentists and allied health staff when treating people with disability.

Yet lived experience shared with us shows that it is common for people with disability to experience negative attitudes and discriminatory behaviours from medical professionals.

For example, in Inclusion Australia's submission to the Disability Royal Commission, people with an intellectual disability reported being ignored by medical professional and have their family members or support workers expected to speak for them.⁷⁵ It is common for information to be withheld from people with disability based on ableist assumptions—whether intentional or not—that a person does not have the capacity to understand what a procedure involves or what kind of treatment options are available to them.⁷⁶

R is a person with an intellectual disability.

We need written down information from a dentist so we know what the procedure is about and what we can and can't do before or after. I went through so much uncertainty when I had to have my wisdom tooth removed.

People need Easy Read information all about the procedures so they can be informed and know that everything will be ok.

⁷⁵ Inclusion Australia. (2020). Submission to the Disability Royal Commission – The Omnibus. p. 51-54. Retrieved from: <https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-the-omnibus/>

⁷⁶ Inclusion Australia. (2020). Submission to the Disability Royal Commission – The Omnibus. Retrieved from: <https://www.inclusionaustralia.org.au/submission/submission-to-the-drc-the-omnibus/>

E is the mother of a daughter with an intellectual disability, J.

It was easy enough to get an appointment, although it was a trek to get there because we live so far away from the only special needs public clinic in Perth.

The dentist who saw us called J a “naughty girl” because she wouldn’t open her mouth wide enough. This is a 7-year-old child with a severe intellectual disability mind you.

And then there was a team of nurses all acting ridiculous thinking it would make J laugh—just going about showing her noisy squeaky toys, the kinds you might use to make a baby smile, not age or disability appropriate at all. J was just so overwhelmed and lost the plot.

Her teeth were all ground down and rotten from a pretty limited diet—it’s difficult when your kid only eats 3 foods and won’t let you brush their teeth! And the dentist just said “it’s fine, they’re her baby teeth they will all fall out and her adult teeth will be fine”. Which I later found out is not true at all, it does affect their adult teeth.

One pathway to providing informed consent is through Supported Decision Making. Under Article 3, Article 4 and, more recently, Article 12 of the UNCRPD, which is about equal recognition before the law,⁷⁷ all people have rights to make their own decisions, including the decision to change their mind.

Supported Decision Making is a way of thinking and relating to others that respects peoples’ rights to make their own decisions. It assumes all people have the capacity to make their own decisions to the maximum extent possible.

There is a growing number of freely available, often co-designed Supported Decision Making practice models that build capacity within decision-makers and decision-supporters to actualise and uphold peoples’ rights under the UNCRPD. In the context of dental care, this also means enabling peoples’ rights to be involved in planning for treatment options; to be informed on all aspects of their dental care; to decide to give or withhold consent for any aspect of their treatment; and the right to change their mind.

The Australian Law Reform Commission (ALRC) has suggested ways to make these rights part of Australian law and have produced a set of National Decision-Making Principles:

1. All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
2. Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.
3. The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

⁷⁷ Article 12 – Equal recognition before the law. *United Nations Convention on the Rights of People with Disabilities*. Retrieved from: [Article 12 – Equal recognition before the law | United Nations Enable](#)

4. Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.⁷⁸

The ALRC principles were made to guide reform of Australian laws and policies.

Recommendations

10. Ensure all people have access to Supported Decision Making at the dentist as a pathway to the provision of genuine informed consent and choice and control over their oral health

Do this by embedding the Australian Law Reform Commission (ALRC) National Decision-Making Principles within the forthcoming 10-year *National Oral Health Plan* and a revised version of the National Safety and Quality Health Services (NSQHS) Guide for Dental Practices and Services.

⁷⁸ Australian Law Reform Commission. 2014. National Decision-Making Principles. Retrieved from: <https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/3-national-decision-making-principles-2/national-decision-making-principles-2/#:~:text=3.5%20The%20National%20Decision-Making%20Principles%20are%20four%20general,but%20reflect%20and%20are%20informed%20by%20those%20p rinciples.>

Case studies

The following case studies have been gathered from the communities of people we represent.

These case studies present critical evidence based on the lived experience of people with disability and family members. They demonstrate how the barriers discussed in this submission impact the real lives of people and reveal the damaging systemic settings in which people are trying to access the critical dental care they need.

CYDA'S case study – 'Zeta'

This section outlines the barriers faced by a child and their family in accessing affordable, inclusive and timely dental care through a real-life case study. A pseudonym, Zeta, has been used to protect the identity of the child and their family. Families and young people advise us that there can be harsh repercussions when their identity is not protected.

The case study of Zeta details how a major barrier to oral health care for children with disability is a lack of trained oral health practitioners. This has resulted in Zeta:

- o Missing out on preventative dental care and regular check-ups
- o Being unable to access required dental treatment in timely and safe environment
- o Being unable to build a trusting relationship with a dentist
- o Missing out on continuity in oral health care
- o Suffering stress and trauma from dental visits

This case study is representative of the challenges that children and young people with disability experience. Children and young people with disability do not receive regular dental care.⁷⁹ Oral care practitioners often lack knowledge and training of disability or have inadequate resources, which mean they are unwilling or unable to meet the needs of this cohort.⁸⁰^[2] The relationship between poor oral health and positive health, wellbeing and quality of life is well documented in this submission.

Zeta and her family's story

Note from the family in this case study:

Zeta is a loved and loving member of our family. She is our second child. She has a rare genetic disability that impacts her physical, social, emotional, communication and cognitive engagement with everyday life. She has for the most part a very ordinary childhood. She goes to the same school as her older brother did.

⁷⁹ Lopez Silva, CP, Singh, A, Calache, H, Derbi, HA & Borromeo, GL 2021, "Association between disability status and dental attendance in Australia—A population-based study," *Community dentistry and oral epidemiology*, vol. 49, no. 1, pp. 33–39.

⁸⁰ Lim, MAWT, Liberali, SAC, Calache, H, Parashos, P & Borromeo, GL 2021, "Perceived barriers encountered by oral health professionals in the Australian public dental system providing dental treatment to individuals with special needs," *Special care in dentistry*, vol. 41, no. 3, pp. 381–390.

She attends after school hours care two days a week. She pats our dog, fights with her brother over the remote control, and raids the fridge when she's hungry.

Public and private health admissions and services:

Over the last 11 years we have navigated the public and private health systems punctuated with a key theme of limited communication between the two systems. Zeta has at one time been under the care of the following (not an exhaustive list):

1. GP
2. Paediatrician
3. Neurologist
4. Cardiologist
5. Endocrinologist
6. Anaesthetist
7. Respiratory and Sleep physician
8. Ear Nose and Throat specialist
9. Gastroenterologist
10. Orthopaedic surgeon
11. Plastic surgeon
12. Dietician
13. Speech therapist
14. Physiotherapist
15. Occupational therapist
16. Paediatric dentist

Dental care:

There are a number of necessary medical scans and examinations that Zeta should have regularly that have not been possible. This includes dental check-ups.

“Our child needs a dentist who can listen, learn and adjust. Is that too much to ask?” – Mother of child, case study Zeta

Zeta needs a dentist that is willing to make reasonable adjustments for a patient who uses augmented and assistive communication, has an intellectual disability and who has had bisphosphonates previously. Our youngest child, now 11 years old, has never had a full dental check-up other than under a general anaesthetic. We have struggled to connect with a dentist – public or private - who is able to offer a service that meets her needs.

She needs a dentist that can listen to her previous experiences, direct from her mother, adapt and modify their communication and approach to match the child's response. She needs a dentist that won't create trauma but learn from previous experiences and adapt.

Cost:

We have probably spent more than \$4,000 to get to this point. Our family has had private health insurance with dental cover long before both of our children were born. We dropped all extras (dental included) when it became obvious that none of the dental work needed (for any of the 4 members of our family) would be covered to an adequate level to justify the premiums paid.

Communication and data:

There is no one health person who has carriage or knowledge of Zeta. We as parents are required to hold and communicate the knowledge – medical and otherwise – between professionals and systems. All professionals in Zeta’s life correspond by letter with each other before and after appointments as part of the referral process. This is often the extent of the communication and there is no one case manager – other than her parents.

Experience:

*“Affordable? No. Accessible? No. Timely? No. Inclusive? No.
Necessary? Absolutely.”
– Mother of child, case study Zeta*

We (Zeta’s parents) have both regularly accessed private dental services, as well as our oldest child. We knew that it might be a little bit different for our youngest child, but we had not expected to find it so hard. Our oldest child had experienced some great dental care, both communication and approach, and we assumed that a similar approach would be taken by those billed as paediatric specialists. We were wrong.

Dentist A: (billed as a paediatric specialist)

Without any communication the dentist wrenched Zeta backwards, while in her wheelchair, and pried her mouth open. My child was extremely upset and we did not return to this dentist.

Dentist B: (billed as a paediatric specialist)

We visited dentist B and my child would not open her mouth to the dentist and so we organised a general anaesthetic (GA) at a private children’s hospital to investigate. It included x-rays and a full clean.

Public dentist:

Via the public system paediatrician, Zeta was able to access the dentist at the local children’s hospital. She would not open her mouth to the dentist and we were advised that a GA would only be organised if there was a specific issue and not for a general clean.

Dentist C: (billed as a paediatric specialist)

We visited dentist C and my child would not open her mouth to the dentist. We attempted to organise an investigation and clean under GA with dentist C. The final result was they refused to go ahead with the

investigation as they were not prepared to remove any teeth (if required) because of her previous bisphosphonates. We had no evidence to say she needed teeth removed but the dentist would not proceed.

Dentist D:

We have begun building a relationship with our local dental practice, attended by our other child and one parent. They are a general dental practice who would need to refer us elsewhere for any work under GA. The practice is prepared to build a relationship with Zeta, accommodating her method of communication, her need to build trust with them, and ultimately let her set the pace. This should have been available to her from age 3, when we first visited a dentist.



“Our child needs proactive dental care with a trusted person and in a place that is welcoming. We don’t believe it is necessary to wait until something is wrong. Reactive dental care means her quality of life has already been negatively impacted.” – Mother of child, case study Zeta

Inclusion Australia - Case study: a family member's perspective

D is a disability advocate and the mother of an adult son with disability, H. She told us about her experience supporting her son to receive dental treatment:

H was in desperate need of a dental check-up. With all that we do to maintain our teeth—he was living in supported accommodation at the time, so that hadn't happened.

We went to a major public health clinic situated at a hospital here in Melbourne. He was in his 20s at the time. We had managed to get in because they run clinics on certain days for people with disability. And so we rocked up for one of those clinics and managed to get H to sit in the chair with a small amount of sedation.

The dentist had a quick look in his mouth and said H's teeth were pretty bad. He said, you know, I could do some work on them but my feeling is we take them out so they don't continue to cause any problems with pain and whatever.

And then the dentist said to me—he actually made this statement in front of H—“we take these guys' teeth out all the time, and they do fine”.

He was referring to 'these guys' as people with disability, saying 'they cope just fine without their teeth'.

And I just felt sick. Literally—and I'm feeling a bit sick as I'm talking about it now. That this was the attitude from a senior medical professional. I was just gobsmacked.

I could have said a whole lot of things, but my way of responding was just to never go back.

After a number of years, H did end up having his teeth removed. D describes how this impacted H's life:

H was stressed for a long time, not having his teeth. He talks about it periodically, he talks about getting new teeth. Yeah, it was pretty traumatic, but interestingly it also caused some problems for him in terms of how people judged him and saw him.

Because, you know, when he's out and about in the community, for quite a few years after it happened, people would assume he was a drug addict—those words were actually used. So it affected the image that he presented. So there were social challenges as a consequence of the dental treatment.

Down Syndrome Australia - Our experiences

Down Syndrome Australia's Health Ambassadors are a group of individuals with Down syndrome, who work to inform health care workers about how best to include people with Down syndrome in their own health conversations.⁸¹

Below are some stories shared by DSA Health Ambassadors.

Caitlin, DSA Health Ambassador

Last year when I went to the dentist, I was sitting in the dentist's chair. The dentist was talking to my Mum and suddenly the chair moved down and I bumped my head. I didn't know this was going to happen and I had a real fright. It is important that healthcare workers take time to communicate so I understand. If the dentist had explained to me what he was going to do before he put the chair down I would have not have gotten a fright and felt so nervous.

Kim, DSA Health Ambassador

Recently, I needed my wisdom tooth removed. I was very worried about this, but when the doctor explained the procedure and communicated with me so that I understood, I felt much more relaxed.

It's important for health workers to speak clearly and explain in a way that I can understand, use simple, everyday language. It's important for health workers to realise that I might be a little bit scared of what is happening to me and tell me what is going on. When I understand it makes me feel more comfortable and I can answer questions better. This will help any health care worker who is treating me to find the right problem and do their job better, and then I can get better quicker.

Naomi, DSA Health Ambassador

Last year I had to have a tooth extracted from the roof of my mouth. This was a very scary thought for me. When we arrived at the hospital the receptionist asked mum to fill out a form about me! She didn't speak to me, even though mum gave me the form to complete. I felt unhappy about being ignored and not involved. It made me feel more anxious.

As I sat in the waiting room with mum and dad, I was very nervous about what was going to happen. When the nurse called me to go into the theatre I asked if dad could walk with me to help me stay calm. I tried to explain this to her, but she had no empathy or understanding and just said NO dad couldn't come. She said that she'd had lots of patients with Down syndrome and that I would be fine. She didn't treat me as an individual and made me feel like I didn't exist. She needed to give me time and she needed to have patience. She needed to make sure I understood what was going to happen.

Understanding people with Down Syndrome, is beneficial for [health professionals] learning and professional development. It will also make their job easier if they treat us as individuals. ALL people have the right to the same quality of care.

⁸¹ For more information, please visit <https://www.downsyndrome.org.au/advocacy/health-ambassadors/>

DSA's Queensland Down Syndrome Australia Network (QDSAN) ran a small focus group and shared the following points about access to dental care:

Good/bad experiences with dental care:

All of the QDSAN members have been having good experiences with their dentists. The reasons for this have been because:

- The dentist knows the person well
- Parents/support people have been very involved in the prep and attendance at appointments
- Dentists have explained to the person what is happening in the appointments

Some of the barriers could be:

- Anxiety about going to the dentist because the person might not know what is happening (i.e. they haven't been prepped or told what is going to happen/what can be expected)
- The person not being able to communicate how they are feeling during appointments

Ideas for improvement:

- For the person to be supported to build their capacity to go to the dentist through their NDIS plan – Decrease the anxiety and increase confidence; how best to communicate their needs in appointments
- There were also a few that mentioned that the NDIS should pay for their dental bills, or they should be subsidized in some way

Examples of best practice

This section will briefly explore several SND initiatives that incorporate some of the elements of best practice previously highlighted in this submission, including collaboration between community dentists and specialists; reduced reliance on specialist services; integrating oral health care into primary health care; increased focus on preventative care; education and training of carers; and promoting SND in dental curricula.

Collaboration between specialist dental providers and community dental clinics

Special Needs Network (South Australia, Australia)⁸²

- **What is it?** The Special Needs Network facilitates collaborative partnerships between specialist practitioners working within the Special Needs Unit (SNU) at the Adelaide Dental Hospital and upskilled dentists within the community, enabling patients with disability to access care more conveniently and within a familiar setting. This also ensures that only the more complex cases truly requiring treatment within a hospital setting are referred for specialist care at the SNU, thereby freeing up specialists' limited time.
- **Why it works?** The specialist practitioners support dental clinicians working within their local communities, fostering close collaboration between the Adelaide Dental Hospital and local dental clinics. This promotes upskilling of dental clinicians and alleviates reluctance to treat people with disability; a major barrier to accessing dental care. As a result, people with mild to moderate disability are able to be treated at their local clinic, while only those more complex cases are referred to specialist care.

Mentoring for clinicians by SND specialists (Australia – multiple locations)⁸³

- **What is it?** Multiple dental clinics across Australia have explored mentoring as a means of supporting clinicians and reducing unnecessary referrals to specialist services for people with disability. While commonplace in other areas of health care, mentoring has seen limited use in dentistry; an issue that may stem from the historical separation of dentistry from other aspects of healthcare. A qualitative evaluation of these mentoring programs was conducted to establish whether they would improve the willingness of clinicians receiving support to attempt treatment of people with disability, rather than immediately referring them to specialist care.

⁸² Lim, M.A.W.T., Liberali, S.A.C. & Borromeo, G.L. Utilisation of dental services for people with special health care needs in Australia. BMC Oral Health 20, 360 (2020). <https://doi.org/10.1186/s12903-020-01354-6>

⁸³ Lim MAWT, Liberali SAC, Calache H, Parashos P, Borromeo GL (2022) Mentoring of oral health professionals is crucial to improving access to care for people with special needs. PLoS ONE 17(4): e0266879.

- **Why it works?** The mentoring program enabled clinicians to interact directly with specialists in the manner that best suited them, be that seeking advice on specific cases, direct observation, joint consultations and treatment planning, role modelling, or receiving moral support. In addition, working alongside specialists in the community clinics enabled clinicians to see how specialists adapted to a local setting and its possible limitations with regard to infrastructure, clinic design, equipment, and facilities. As a result of this mentoring, clinicians became more willing to work with special needs patients rather than immediately referring them on, reducing the burden on already limited specialist resources.

Integration into primary health care

Morogoro rotation (Tanzania)⁸⁴

- **What is it?** The Morogoro rotation is an initiative under the stewardship of the World Health Organisation (WHO) as part of their focus on Primary Oral Health Care (POHC), a method that looks to integrate oral health care with primary health care generally. The program is part of the Doctor of Dental Surgery (DDS) curriculum at Muhimbili University of Health and Allied Sciences (MUHAS) in Tanzania. It consists of community participation field rotations wherein students are given the opportunity to undertake work experience within rural schools and reproductive child and health clinics. The rotation encompasses various tasks, including establishing cooperative working relationships with the respective communities, facilitating oral health examination exercises in the field, coordinating oral health education sessions, promoting oral health care, and delivering emergency oral care. At the end of their rotation, each student has the opportunity to spend two weeks working with the regional dental officer at any regional dental clinic in the country.
- **Why it works?** Upon graduation, these students will work as team leaders overseeing POHC in a given region. The community field rotations enable them to gain the requisite knowledge and leadership skills required to take on this responsibility. Graduates of the program will also begin their dental careers with an understanding of the importance of both POHC and the necessity of integrating oral health care with primary health care.

⁸⁴ Prasad M, Manjunath C, Murthy AK, Sampath A, Jaiswal S, Mohapatra A. Integration of oral health into primary health care: A systematic review. J Family Med Prim Care 2019;8:1838-45.

Oral hygiene education for caregivers

Smiles for Life (Sydney, Australia)⁸⁵

- **What is it?** The Smiles for Life education workshop was an initiative by the Department of Special Needs Dentistry (Special Care Unit) at the Westmead Centre for Oral Health that occurred between the years of 2014-2018. It consisted of an oral health education seminar aimed at paid and unpaid caregivers, with an emphasis on the importance of a multidisciplinary approach when caring for the oral health of patients. The content included an introduction to oral health as a part of general health, oral diseases, oral hygiene instruction, dietary advice, and denture care and maintenance, and was followed by a practical workshop covering tooth brushing methods, retraction techniques, use of appropriate oral health products, and behaviour management strategies.
- **Why it works?** While an evaluation of the Smiles for Life program did not demonstrate an increase in the oral health literacy of caregivers, it provided many important learnings that can be used to inform future initiatives. In particular, the pilot demonstrated that programs must be tailored to suit individual types of carers, taking into account both their level of health literacy and the types of disability they encounter, rather than employing a generic, 'one size fits all' model. The importance of co-designing with both carers and people with disability was also raised as a necessary factor in the success of any future programs.

Education and accreditation initiatives

Commission on Dental Accreditation (CODA) (USA)⁸⁶

- **What is it?** CODA was established in 1975 as the sole agency accrediting dental and dental-related education programs at the post-secondary level in the United States. This includes predoctoral dental education programs, advanced dental education programs, and allied dental education programs. CODA also accredits predoctoral programs internationally. Its purpose is to develop and implement standards that promote and monitor the continuous quality and improvement of dental education programs.
- **Why it works?** Research has indicated that predoctoral curricula around the world fail to adequately cover SND, leaving many dental students unprepared and thus reluctant to work with patients with disability. The standards established by CODA emphasise the importance of

⁸⁵ Wilson, N.J.; Patterson-Norrie, T.; Bedford, C.; Bergstedt, N.; Mendoza, L.M.; Villarosa, A.R.; George, A.; Karve, A. Evaluation of Smiles for Life: A Caregiver Focused Oral Health Education Programme. *Disabilities* 2022, 2, 564–574. <https://doi.org/10.3390/disabilities2040040>.

⁸⁶ Alumran, A, Almulhim, L, Almolhim, B, Bakodah, S, Aldossary, H & Alakrawi, Z (2018) Preparedness and willingness of dental care providers to treat patients with special needs, *Clinical, Cosmetic and Investigational Dentistry*, 231-236. DOI: 10.2147/CCIDE.S178114.

ensuring students have clinic experience with SND as part of their education, stating: “graduates must be competent in assessing the treatment needs of patients with special needs.”

Community Engagement Model (UK)⁸⁷

- **What is it?** At the University of Plymouth's Peninsula Dental School, an integral component of the curriculum is their community engagement module. This module offers students an opportunity to work directly with vulnerable members of the community who are more likely to experience health disparities and suffer from poor oral health. Through this engagement, students are tasked with developing and implementing interventions tailored to the specific needs of their target population.
- **Why it works?** The module provides students with experiential learning opportunities, enabling them to develop their clinical and interpersonal skills while imparting a broader understanding of public health issues and the impact of health inequalities. Evaluation of the module has shown demonstrable mindset and attitudinal changes, including increased confidence and willingness to work with special needs patients and other target populations.

⁸⁷ Witton, R & Paisi, M (2022) The benefits of an innovative community engagement model in dental undergraduate education, *Education for Primary Care*, 33:1, 41-45, DOI: 10.1080/14739879.2021.1947160.