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8 February 2021

The Inquiry Secretary
Parliament House
HOBART TAS 7000

Via email - dst@parliament.tas.gov.au

Dear Sir/Madam

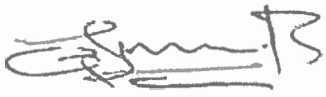
The Australian Dental Association Tasmanian Branch (ADATB) endorses the joint submission by The Disability and Oral Health Collaboration, Your Dental Health project team and the Australasian Academy of Paediatric Dentistry previously provided to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability, a copy of which is attached.

In addition to the items raised, the Branch would further recommend that oral health assessments be included in periodic care plans for facility residents. An initial assessment of each potential resident prior to admission to the facility would help identify their ongoing dental care needs.

It is concerning to note that currently, dental visits to facility residents are not mandatory. Inclusion of oral health assessments within facility care plans would be an appropriate addition to the National Disability Services Scheme to achieve this outcome for residents.

Professor Len Crocombe, Australian Dental Association Branch Councillor, would welcome the opportunity to attend the Inquiry to provide a presentation or answer any questions. Please contact Mrs Maree Horseman, ADATB at maree.horseman@adavb.org to make arrangements.

Yours sincerely



Dr Girish Sasidharan
President
Australian Dental Association
Tasmanian Branch

Encl

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Joint submission from:

Disability and Oral Health Collaboration (DOHC)

Deakin University, University of Melbourne, Inclusion Melbourne, Australian Society of Special Care in Dentistry (ASSCID), North Richmond Community Health (NRCH), and Autism Queensland.

Your Dental Health (YDH) project team

Inclusion Melbourne, Monash Health, Carrington Health, Dr Richard Zylan.

Australasian Academy of Paediatric Dentistry (AAPD)

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On 30 August 2019, members of the Disability and Oral Health Collaboration (DOHC) and a number of associates with disability met together with Commissioners Galbally and McEwin at Deakin University's Downtown Campus in Melbourne.

This meeting provided the DOHC with an opportunity to highlight some of the issues relating to oral health for Australians with disability, with a specific focus on intellectual disability, and the work currently in progress by DOHC members. Commissioner McEwin described the meeting as a "gathering of critical experts". This submission represents the distillation of this critical interdisciplinary expertise following many years of collaborative work and practice.

1. Oral Health and Disability: An Overview

Oral health is central to overall wellbeing. Good oral health is required if people with intellectual disability (ID) are to experience good general health, participate in their communities, and function to the best of their abilities. The consequences of neglecting oral health are serious and include pain, infection and loss of teeth, leading to functional difficulties with diet, speech and behaviour, as well as severe systemic health issues. The risks and costs of providing dental interventions should also be considered.

a. Neglect and abuse

Signs of neglect and abuse often manifest in the head and neck region, and oral health professionals should be part of the interdisciplinary team addressing such issues.

Dental and oral soft tissue injuries caused by physical and sexual abuse can be hidden from view, and oral health professionals are well placed to identify such signs of violence. Furthermore, people who have been subject to oral trauma can develop defensive behaviours that affect their daily oral care. Development of trust and rapport with their carers and oral health care providers is necessary for maintaining their dental health and supporting them to overcome their fears.

b. Gaps in support

People with cognitive impairment often require additional support in order to participate in decision making regarding their dental treatment. Many are reliant on a substitute medical decision maker to provide consent for some or all of their dental treatment. Where communication between clinicians and decision makers is inadequate or inefficient, people with ID are at greater risk of over-treatment, under-treatment, treatment provided without respecting their wishes, delays in management and other forms of unsuitable care.

People with ID can also have difficulties cooperating with oral care, leading to the use of physical and chemical restraint to facilitate their dental treatment. The use of restrictive practices in the delivery of oral care is an area of concern affecting their human rights and access to care. The DOHC has identified a sizeable gap in practice and regulation between disability legislation, disability support practice, and dentistry.

Greater collaboration between the disability and dental sectors will be required in order to overcome these challenges and improve the delivery of oral health services with people with ID. This needs to be supported by education, workforce training, funding and government policy.

People with disability are at increased risk of poor oral health and face multiple barriers to accessing dental services. While diagnosis is important, particularly for people whose specific conditions have associated comorbidities, it must be recognised that the barriers to oral health experienced by most patients with intellectual disability relate to social, cognitive, communication, motor, sensory and behavioural factors rather than their formal diagnosis of disability. For most, the experience of disability is defined by social exclusion and the disadvantage caused by socioeconomic disadvantage, societal assumptions and a lack of support, rather than medical or functional diagnoses. A lack of dentists with adequate skills in managing people with a disability was the most frequently reported problem in obtaining dental care, followed by cost of dental treatment, and transportation difficulties, especially for wheelchair users (Pradhan et al. 2009). The solutions therefore lie in adopting a bio-psycho-social approach to assessment and intervention, as advanced by the World Health Organisation (WHO).

c. Lack of data collection

Unfortunately, there is a lack of national data regarding the oral health needs of people with ID. The Australian Government conducts National Oral Health Surveys every few years. These surveys are

published and help inform policy development at a Federal level. These surveys have not captured the baseline oral health status of people with disabilities, due to sampling and other issues. ASSCID has been advised that it is too difficult to capture this information on these surveys. The Federal Government has not accepted the data which is available (which overwhelmingly shows poorer oral health status for people with Developmental Disabilities compared to the general population) because it comprises small studies and not national data. This lack of data, and a proven methodology with which to collect it, is a critical barrier to evaluating interventions and program outcomes over time.

d. The unique needs of people with intellectual disability

Intellectual disability occurs on a spectrum, and those affected vary greatly with respect to their risk of developing oral disease, and their ability to cope with dental treatment. The dental needs of patients with a disability are, in many cases, greater than other patients in the general community. In addition to their cognitive impairment, people with ID often have associated medical conditions, physical disabilities and psychiatric conditions which impact on their ability to clean their teeth, maintain a healthy diet, and cooperate with dental care. They may be at greater risk of dental wear from tooth grinding or oral trauma from abuse, falls and self-injurious behaviour. Many people with ID require medications that reduce saliva flow, greatly increasing their risk of decay (dental caries). Some conditions (e.g. Down syndrome) are associated with immune system limitations that increase the risk of periodontal (gum) disease. People with more severe ID may have difficulty recognising oral health problems and communicating the need to see a dentist. Preventive care is critical and dental health assessments should be provided routinely, rather than in reaction to a suspected or identified problem.

Due to differences in their risk of oral disease and the ability to understand and tolerate dental procedures, the approach used for planning dental treatment for a person with an intellectual disability should be adapted to their individual needs. Modifications may include:

- Additional attention given to communication and consent.
- More frequent need for dental checks and preventive services such as cleaning and fluoride application.
- Creative solutions for addressing individual barriers to oral health and care such as anxiety, needle phobia, post-traumatic stress disorder, sensory sensitivities, taste aversions, a strong gag reflex, poor oral hygiene and unhealthy dietary habits. Multiple appointments may be required for education, familiarisation and desensitisation.
- Altering the environment in which the person receives dental care (e.g. at home rather than in the dental surgery; providing low-sensory treatment rooms and non-clinical spaces).
- Greater need for communication and coordination of care between the patient, their family and/or carers, guardians, financial administrators, support professionals (including support accommodation supervisors and direct support workers) and other health and allied health professionals.

Existing public and private dental practice models and funding often do not support the additional time and resources required by general dental practitioners to provide effective oral care for people with ID, and there is a lack of funding to support dental involvement in multidisciplinary interventions. Practical difficulties with providing costly and complex dental interventions requiring long periods of time or multiple appointments may lead to unwanted outcomes such as:

- patients receiving extractions rather than fillings
- increased severity of periodontal disease
- a lack of functional replacement of extracted teeth
  (Mac Giolla Phadraig et al., 2014)

Dental extractions and lack of tooth replacement do not necessarily reflect dentists' lack of management skills or clinically inappropriate care. These outcomes may be a result of care provided within the limitations of the patient's medical history, capacity to cooperate and the resources available to provide treatment. However, dental decay and gum disease is largely preventable with adequate oral hygiene and dietary control, and these findings clearly demonstrate a failure in routine preventive home care.

Dentistry is a 'whole of life' issue and everyone, including those with ID, benefits from ongoing regular professional recall and preventative and maintenance programs. The consequences of not adequately supporting good oral health in people with disability include:

- localised problems such as decay, gum disease, excessive tooth wear, oral fungal infections, bacterial infections, pain, poor appearance and loss of teeth
- functional difficulties with eating, drinking, smiling and speech
- urgent systemic health issues which can include sepsis, compromised airway and swallowing difficulties, malnutrition, dehydration and aspiration pneumonia
- complications related to dental procedures such as bleeding, post-operative infections, osteonecrosis of the jaw and aspiration
- complications related to sedation and general anaesthesia
- psychological trauma from invasive dental procedures undertaken without adequate preparation
- increased financial burden on individuals, families and the health system.

e. Oral health and overall health in people with intellectual disability

While poor oral health is a significant health concern in itself, the link between oral and systemic health is also well established in literature. Poor oral health has been linked to increased risk of cardiovascular disease, diabetes and other chronic conditions (Bascones-Martinez 2012). For example, diabetes has been linked to the presence of periodontal disease (Bascones-Martinez 2012) with patients having "six times higher risk of worsening glycaemic control and the development of the macro and microvascular complication of diabetes, in particular cardiovascular and kidney disease" (Watanabe 2011).

Inflammation constitutes a major mechanism for the observed link between oral diseases, specifically periodontitis, and several particular systemic diseases. There is evidence for an association between periodontal disease and diabetes, as well as emerging evidence for other conditions including: obesity; coronary artery disease; metabolic syndrome; [poor] oral health after menopause; helicobacter pylori; [and] adverse pregnancy outcomes (Sievers et al., 2010:17).

Recent research in Australia and the UK further demonstrates the dire link between disability (particularly intellectual disability) and poor overall health, of which oral health is now understood to be a contributory factor.

For example:

- Potentially avoidable deaths occur at twice the rate of the general population, with leading causes being circulatory system disease, infections and cancer, coupled with less rigorous care and fewer allied health referrals. (NSW: Trollor et al., 2016)
- More than a third of deaths are potentially amenable to health care interventions (UK: Hosking et al., 2016).
- Lower life expectancy findings in global research include:
    - Age adjusted mortality ratio for people with intellectual disability twice that of the general population (UK: Heslop & Glover, 2015)
    - 22% of people with intellectual disability die before age 50, compared with 9% of the general population (UK: Heslop et al., 2016).
    - Gap in life expectancy 13 years for males and 20 years for females (UK: Heslop et al., 2016)

In addition to serious systemic health issues, unrecognised oral health can lead to other complex outcomes. For example, a person with intellectual disability and non-verbal communication may experience severe gum or tooth pain but be unable to communicate this pain to staff, carers or friends in a manner that is immediately understood. It is entirely reasonable to expect this communication to occur through 'behaviours of concern' (where the person's behaviours can cause harm to themselves or others, or damage to property; see discussion below) that are misunderstood and result in the inappropriate use of *restrictive practices* (i.e. physical, mechanical and chemical restraint, seclusion, or a range of environmental restraints) that can cause further harm and breach people's civil and human rights. The person's poor oral

health may go relatively unnoticed other than through bad breath and, eventually, issues related to appearance and behaviour that impact on social engagement. Here it should be noted that these 'behaviours of concern' can be an indicator of poor oral health and a barrier to receiving the oral health care necessary to prevent or address these behaviours.

f. The disability support sector and dentistry

Australian research has found that carers are often unable to report oral health related quality of life (OHRQoL) for a significant proportion of those with little or no effective communication skills. Therefore, carers need to be made aware of the negative impacts of oral problems and trained to identify them by observing behavioural changes at an early stage to reduce the suffering caused by advanced disease and to improve OHRQoL (Pradhan 2012).

There are 6 primary units available to students undertaking Vocational Education and Training Courses such as Certificates III and IV in Individual Support (Aged Care and Disability). However, the vast majority of support professionals working in the disability sector have not completed these modules. Furthermore, the Your Dental Health project (discussed further below) has found that only a small but strategic set of oral health skills is required for the typical support professional working in community or residential settings in order to play a beneficial role in the interdisciplinary oral health care of people with ID. These skills include:

- visually identifying oral problems in people with ID
- discussing oral health with people with ID
- supporting home preventive care as directed by an Oral Home Care Plan
- basic planning of regular appointments, including clear communication with administration staff at local dental practices
- working with people with ID whom they support to prepare for appointments
- ensuring Oral Care planning documents are used, reviewed, and communicated to relevant allied health professionals

Regardless of the uptake of accredited training units by direct support professionals, many of these planning, observation and direct support skills are also part of evidence-based direct support practice frameworks, such as Person Centred Active Support (PCAS), that should already be employed by disability support organisations.

It is reasonable to suggest that many oral health professionals who engage with disability support professionals (for example, when a support professional accompanies a person with ID to a dental appointment) may develop the opinion that the direct support sector does not have the capacity to consistently engage with interdisciplinary oral health processes. However, a collaborative pathway that effectively connects support professionals, dentists and dental practice administration staff (such as the pathway outlined in *Oral Health and Intellectual Disability* discussed further below) need not be seen as out of reach, but rather a genuine and quite achievable solution to the severe neglect of the oral health of people with intellectual disability in the disability support sector.

The Your Dental Health project has found that many dentists do not have sufficient understanding of the structure, roles and practices of Australia's disability support sector. Some of these knowledge gaps include:

- Positive Behaviour Support, Behaviour Support Plans and Restrictive Practices
- The difference between supported decision making and substitute decision making
- Decision making hierarchies within supported accommodation providers in the disability sector
- The difference between carers and direct support professionals, whereby the latter are subject to significant disability legislation, decision making structures, and practice coaching, while the former are usually unpaid and/or informal and often not subject to the same legislation and systems of the disability support sector
- The various individual planning documents and communication techniques that may be helpful in supporting dentists to navigate the needs of patients with ID

Any plans to systematically upskill general dentists in skills usually employed by specialists in Special Needs Dentistry (SND) must also include building knowledge in engaging with these disability support sector processes.

In light of the above considerations, it is clear that supporting people to improve their oral health involves more than telling them to clean their teeth. Nonetheless, oral health literacy is vital and it is important to work with carers and support workers to empower people with ID with techniques to improve their oral health.

The above information has been adapted from the ADA and ASSCID endorsed publication *Oral Health and Intellectual Disability* (https://inclusionmelbourne.org.au/wp-content/uploads/2019/05/Oral-health-and-disability-web-spreads.pdf) developed by Inclusion Designlab and the Your Dental Health project team. It is imperative that the Royal Commissioners become familiar with this publication.

2. Overview of ASSCID, DOHC, YDH and AAPD

a. Overview of the Australian Society of Special Care in Dentistry (ASSCID)

Special Needs Dentistry (SND), also known as Special Care Dentistry (SCD), is one of the newest Australian dental disciplines, with only 17 specialists in Australia.

The Australian Dental Association (ADA) and the Royal Australasian College of Dental Surgeons (RACDS) define SND as 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." The National Oral Health Plan further acknowledges that patients with special needs have conditions that "increase the risk of oral health problems or increase the complexity of oral healthcare." Internationally, the General Dental Council of the United Kingdom (UK) defines the SCD patient population more broadly as those who have a "physical, sensory, intellectual, mental, medical, emotional or social impairment or disability, or more often, a combination of a number of these factors" thereby including the impacts of living in society.

The Australian Society of Special Care in Dentistry (ASSCID) commenced approximately thirty years ago and was initiated by a small number of dentists with an interest in providing better treatment to people with complex oral health needs (Dr Peter King, Dr Jane Chalmers and Dr Mark Gryst). ASSCID remains a small group of just over 50 oral health professionals and other allied health members. ASSCID is an affiliate member of the Australian Dental Association (ADA).

The aims of ASSCID are:

1. To take an active role in educating the dental profession and other health care workers in the oral health needs of people with special needs.
2. To be a resource centre for oral health professionals seeking information in the management of patients with special needs
3. To lobby for oral health services for people with special needs.
4. To support oral health promotion that targets people with special needs.
5. To be a fraternity of oral health professionals interested in the care of people with disabilities.

b. Overview of the Disability and Oral Health Collaboration (DOHC)

The Disability and Oral Health Collaboration (DOHC) was initiated in 2018 by Professor Hanny Calache (Deakin University, University of Melbourne), Dr Kerrie Punshon (President, ASSCID), Mr Nathan Despott (Inclusion Melbourne), Professor Susan Balandin (Deakin University) and dental and disability academics from Deakin University, University of Melbourne and La Trobe University. Two key outputs of the DOHC have been a systematic literature review (prepared by Dr Tejashree Kangutkar) and several events bringing together members of the DOHC. The collaboration has also attracted research funding from the University of Melbourne's Melbourne Disability Institute (MDI).

The DOHC priorities for action are to:

1. Enhance health literacy (oral health literacy and disability literacy) for dental professionals, non-dental professionals, support workers and carers, and people with disability.
2. Enhance oral health educational programs in the curriculum of health professional courses.
3. Create resources that can be used by groups that teach health professional curricula and can be integrated/incorporated into what is actually being taught in the curriculum.
4. Develop and deliver continuing professional development programs (e.g. masterclasses) for dental professionals, non-dental health professionals, support professionals and carers.
5. Determine feasibility of innovative models of oral health care for people with disability that include reasonable adjustments to care provision.

c. Overview of the Your Dental Health (YDH) Project

The Your Dental Health project is a collaboration between dental health professionals, other health professionals, disability support professionals, and people with intellectual disability (ID), which was formed to develop high quality oral health resources for people with ID.

- The project's resources are available at www.inclusiondesignlab.org.au/dental. Resources include a world-first 'dual read' guide for people with intellectual disability, their supporters and advocates. The site also contains:
    - Three live-action videos of dental procedures in plain spoken English
    - Four short neurodiversity-friendly plain language animations explaining home care, fillings, and orthodontics
    - A message from three dentists to all general dentists discussing the benefits and opportunities for treating patients with ID in the general dental setting rather than referring to other specialists
    - A video demonstrating optimal pre-post interaction between dental practice staff and direct support professionals in the patient's life
- The project also surveyed 100 dentists at the 2017 Australian Dental Congress regarding enablers and barriers to provision of dental healthcare for people with ID.
- One of the barriers identified was a lack of standardised communication between health professionals, disability staff, dental health professionals and allied health professionals. The *Oral Health and Intellectual Disability* Guide was developed to address this issue. The Guide has now been endorsed by the ADA and ASSCID and hard copies disseminated to every dentist in Victoria and WA, with an article and links to the Guide published in the Federal ADA journal.

d. Overview of the Australasian Academy of Paediatric Dentistry (AAPD)

The Australasian Academy of Paediatric Dentistry is an organisation of Specialist Paediatric Dentists whose primary concern is the practice, education and research specifically related to the speciality of Paediatric Dentistry. A prime focus of the Academy is the advancement of the speciality of Paediatric Dentistry and advocacy for the oral health of children and families within our community.

Many of the considerations and conclusions contained in this submission are applicable to the experiences of children with disability. The following additional considerations must be noted:

- The role of untreated dental disease in children and its link to future caries risk potential, poor quality of life parameters, and associated systemic morbidity
- Gaining appropriate consent from parents and guardians
- Gaining equitable access for general anaesthetic and hospital rights for children
- Establishing appropriate DRGs (Diagnosis Related Groups) and co-morbidity data for government to help identify gaps in services/payments and funding, particularly in relation to children
- Expanding MBS codes for treatment of children carried out under general anaesthetic

e. Overview of the Australasian Academy of Special Needs Dentistry (ANZASND)

The Australasian Academy of Special Needs Dentistry is the peak body for Specialists in Special Needs Dentistry in the Australia and New Zealand region. Its purpose is to promote the development of the speciality of Special Needs Dentistry and to advocate for better oral health and clinical care for patients with special needs.

3. Special Needs Dentistry in Australia

Patients referred to public Special Needs Dentistry services in Australia face long waiting times for care. Despite the evident need for more dentists with advanced skills in SND, the barriers to undertaking further education are high. There are only 17 SND specialists in Australia and sharing specialist knowledge with general oral health professionals is difficult due to time constraints. Continuing professional development programs are limited. Some states such as South Australia have successfully implemented a 'hub and spoke' model to facilitate up-skilling, communication, and appropriate referral between a centralised SND specialist unit and community dental clinics. However, such training is not available to all dentists, and not all states have been able to implement such arrangements due to differences in their health care systems. Australia's 10-year National Oral Health Plan (http://www.coaghealthcouncil.gov.au/Portals/0/Australia%27s%20National%20Oral%20Health%20Plan%202015-2024_uploaded%20170216.pdf) does not include enough detail regarding upskilling general dentists to work with people with ID. The last three of Australia's 10-year Oral Health Plans have not met stated targets for improving the oral health of people with a disability. These include upskilling general dentists to work with people with ID, and upskilling people with developmental disability and their families, carers and support workers.

University Specialist Special Needs Dentistry Training programs are affected by budget constraints and not every University in Australia has a specialist training program for Special Needs Dentistry. A few universities without training programs have a designated staff member appointed to teach Special Needs Dentistry to Dental, Oral Health Therapy and Dental Hygiene students, but not all universities have a staff member with a suitable background to teach this area of dentistry. The Australian Dental Council of Australia (ADC) requires all universities to teach this area of dentistry, but programs vary greatly. Not all oral health professionals will have seen patients with ID during their training. This is particularly true of older graduates and those graduating from universities where there is no Special Needs Dentistry specialist on staff.

A review of the ADC SND syllabus requirements may be desirable. There should be a greater focus on collaboration with the International Association for Disability and Oral Health (IADH) and the International Dental Federation (FDI). IADH has membership in countries all over the world and has developed evidence-based, internationally recognised, training resources across a range of subjects relating to oral healthcare for people with ID.

University Specialist Special Needs Dentistry Training programs may cost over $130,000 in fees and are not offered with scholarships. In some universities, the candidates are also unable to earn an income despite providing care for public dental patients as part of their training requirements. Candidates typically have been in the workforce for a number of years and are at a point in their lives where they may have debts and family responsibilities, making the three-year training program difficult to access. Furthermore, career pathways following graduation can be uncertain. Hospitals do not receive Medicare funding for dental services, limiting the capacity to develop positions for staff specialists in SND in tertiary hospitals. This limits the number and circumstances of interested dentists who are actually in a position to enrol in the course.

The focus of Special Needs Dentistry – and the DOHC and Your Dental Health project – is on creating and maintaining good oral health throughout life, rather than relying on emergency treatment for relief of pain in unfamiliar healthcare settings. Developing confidence, familiarisation and positive experiences around dental visits is important yet is frequently overlooked. Emotional support is often required for people with ID undergoing dental treatment generally, and especially as many patients have histories of sexual abuse and assault.

4. Experiences of people with intellectual disability

Cameron, a self-advocate with intellectual disability, typifies much of the experience of people with intellectual disability. Cameron received dental treatment in prison - mainly focused on extractions rather than restorative treatment – and does not remember the details of these extractions. In the two years since he left prison he has not been to the dentist because he cannot afford the visits. His support workers have never discussed his oral health with him and he does not speak to his family or funded advocates about oral health. Cam rarely brushes his teeth though he has no physical impairments preventing him from doing this. He is not aware of public sector dental hospitals or community clinics and has never attended one. He would like dental services to be bulk-billed as part of Medicare.

Karleen, a wheelchair user self-advocate with cerebral palsy and communication barriers, has been proactive in seeking oral healthcare, although it took her several years to find a dentist who treated her 'like a person'. She feels that she has a strong rapport with her dentist, although travel to see the dentist is a barrier as she lives four hours away from this dentist by train and coach. Karleen says that the attitude of staff at the clinic is very important, and good quality dental care takes time and money to plan. It takes time for the dentist to understand Karleen's needs and time for Karleen to communicate them. Karleen has many other competing appointments, so it is easy for dental appointments to not be prioritised.

Dr Richard Zylan is a dentist, a member of the DOHC and Your Dental Health projects and an ASSCID committee member, and the parent of a person with disability living in supported accommodation. He shares the story of a young man living in supported accommodation with major dental issues and poor support from accommodation staff. The young man experiences significant poor overall (or systemic) health and Dr Zylan feels it is highly likely his extremely poor oral health, including gum disease, is a major cause. There is no interdisciplinary focus on the young man's health or oral health. Dr Zylan also notes that he has yet to see an Australian dietary guideline for people with no teeth. "There is poor oral health literacy among carers, while training for support workers is inadequate. It touches on some elements of oral health and nutrition, but interpretation is often left to support workers."

Other self-advocates have frequently indicated to the DOHC and Your Dental Health team that their history of sexual assault has made them wary of health care, particularly dental treatment. Sexual assault of people with disability in group homes and other segregated environments, particularly people with intellectual disability, is extremely prevalent and for some cohorts may represent more than a small minority of patients with an ID.

5. Conceptual and Practice gaps

There are several significant practice gaps that exist between theory and practice within disability, as well as a broader gap between dentistry and the disability support sector. These gaps occur:

- **Within dentistry:** Access to, and flow of, information about treating people with intellectual disability is limited between general dentistry, dental hospitals, and specialist SND services
- **Between dentistry, medicine, psychology, and allied health sectors:** Dentistry is often isolated from other medical and allied health services due to a historical lack of interprofessional education and exclusion from common public funding mechanisms such as Medicare. Interdisciplinary collaboration is lacking. The communication gap between dentistry and medicine means that many people with intellectual disability whose poor general health has been caused or exacerbated by poor oral health could experience significant improvement if their dentists and GPs were to communicate with each other in a consistent and systematic way. See ASSCID and ADA endorsed forms from *Oral Health and Intellectual Disability*, below. There is also a lack of:
    - knowledge in the medical profession about oral health and its importance in reducing/preventing chronic medical conditions and its impact on quality of life of the general population including people with disabilities
    - skills (communication and patient management) among general dental professionals to provide dental care to people with disabilities.
- **Between dentistry and the disability support sector:** Dentists with strong clinical knowledge of disability will only be able to use this knowledge to affect change if they also have a good working

knowledge of the disability support sector. Treatment in the dental surgery must be accompanied by strong planning, communication with the person's supports, and home care. Combined theoretical and practical training and continued support for carers is needed to improve their knowledge and confidence in providing oral care for adults with disabilities (Pradhan et. al. 2016a). The NDIS may have a crucial role to play in supporting home care.

- **Between dental services and people with disability themselves:** Access to dental services for people with disabilities is also an issue as private practice is unaffordable to most people with disabilities and public dental services are limited due to a dental workforce with limited skills in provision of services to people with disabilities, as well as long waiting lists.

Details and implications of these gaps are noted below:

a. Oral health is a generally neglected area in the disability support sector, with staff not able to provide comprehensive pre- and post-planning (ref: pages 8 and 9 of *Oral Health and Intellectual Disability,* https://inclusionmelbourne.org.au/wp-content/uploads/2019/05/Oral-health-and-disability-web-spreads.pdf). In addition, oral health personnel and settings are not always well prepared or trained for patients with intellectual disability.

Planning for quality oral care should be managed through administrative planning. In many ways, **the oral health of people with intellectual disability represents the litmus test of disability support systems as it requires the sound interaction of communication, practice and inter-disciplinary collaboration.**

b. The current NDIS Practice Standards (NDIS Quality Indicators Guidelines 2018) do not address oral health in any specific or meaningful way.

c. The Positive Behaviour Support Capability Framework (developed by the NDIA Quality and Safeguards Commission) does not sufficiently address the considerable intersection of oral health and 'behaviours of concern'. Consequently, oral health is not ordinarily considered as part of the *Functional Behavioural Analysis* (FBA) of people's behaviour support needs and remains unidentified and poorly treated as part of the person's *Behaviour Support Plan* (BSP). It is rare for dentists to be well acquainted with the principles of Positive Behaviour Support, much less Person Centred Active Support and Supported Decision Making.

d. The extent to which oral health issues in people with critically neglected oral health contributes to their poor general health and gives rise to circumstances (e.g., unnecessary use of *restrictive practices*) that compromise their civil and human rights should not be underestimated.

e. When dental professionals do not understand the systems and communication pathways that exist 'behind' the supporters and staff members who accompany a person with ID to dental treatment, they will be unable to effectively engage and utilise the support network.

f. Rather than problematising poor oral health as the fault of the individual, a focus on the broader systemic gaps across the oral health and disability sectors is needed. The practices, systems and tools required to support people with intellectual disability to have good oral health – regardless of their self-care skills – already exist in the various practice frameworks in the disability sector, however the effective training and coaching of these frameworks and the inter-disciplinary communication that is required to connect these practices, systems and tools is lacking.

g. Oral health records need to be communicated to family members, non-dental healthcare professionals, and direct support staff who might not have any training in oral health. The difference in frequency between visits to the dentist and doctor can sometimes be 1:20. Communication regarding oral health needs to occur in a documented and/or recorded manner:

(1) Between people with intellectual disability and their dentist

(2) Between people with intellectual disability and their GP

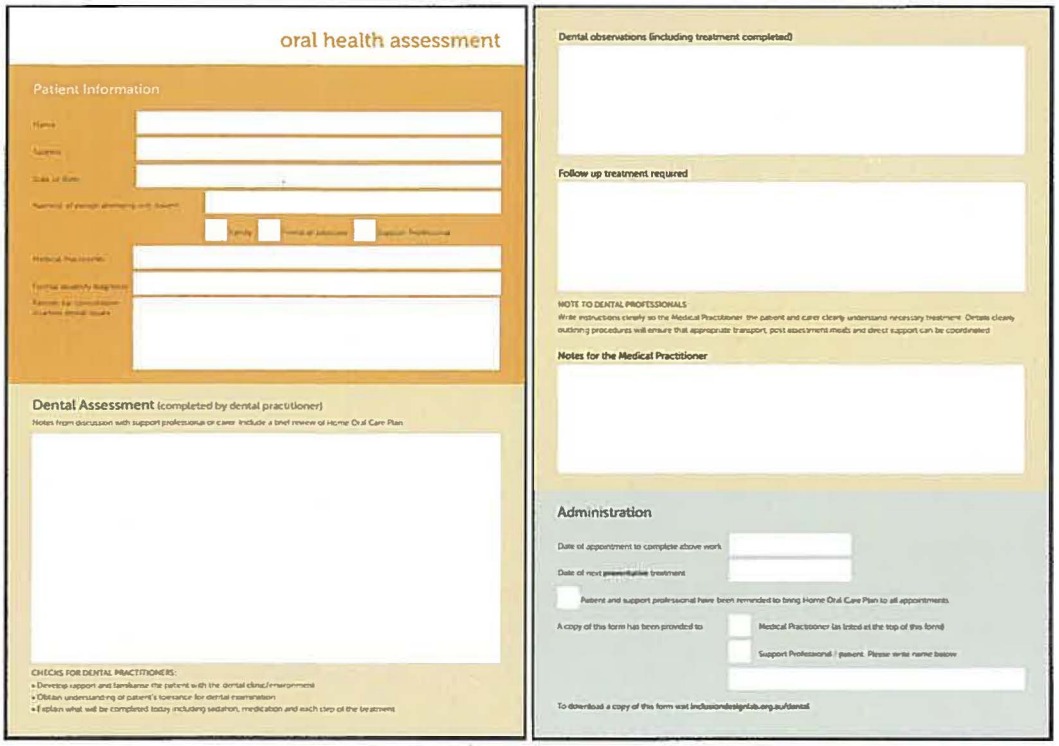
(3) Between supporters and people with intellectual disability

(4) Between dentists and GPs

(5) Between dentists and supporters, particularly accommodation staff and families

(6) Between GPs and supporters

The *Oral Health and Intellectual Disability* Guide contains two high-quality, succinct ADA-endorsed forms that can be used to facilitate communication and treatment planning between (a) dentists and GPs and (b) dentists, people with disability, and their supporters. Thumbnails of these forms are copied below:


oral health assessment

Patient Information

Dental Assessment (completed by dental practitioner)

Notes from discussion with support professional or carer. Include a brief review of Home Oral Care Plan

CHECKS FOR DENTAL PRACTITIONERS:

- Develop rapport and familiarise the patient with the dental clinic/environment
- Obtain understanding of patient's tolerance for dental examination
- Explain what will be completed today including sedation, medication and each step of the treatment

Dental observations (including treatment completed)

Follow up treatment required

NOTE TO DENTAL PROFESSIONALS

Write instructions clearly so the Medical Practitioner, the patient and carer clearly understand necessary treatment. Details clearly outlining procedures will ensure that appropriate transport, post assessment meals and direct support can be coordinated

Notes for the Medical Practitioner

Administration

Date of appointment to complete above work

Date of next preventative treatment

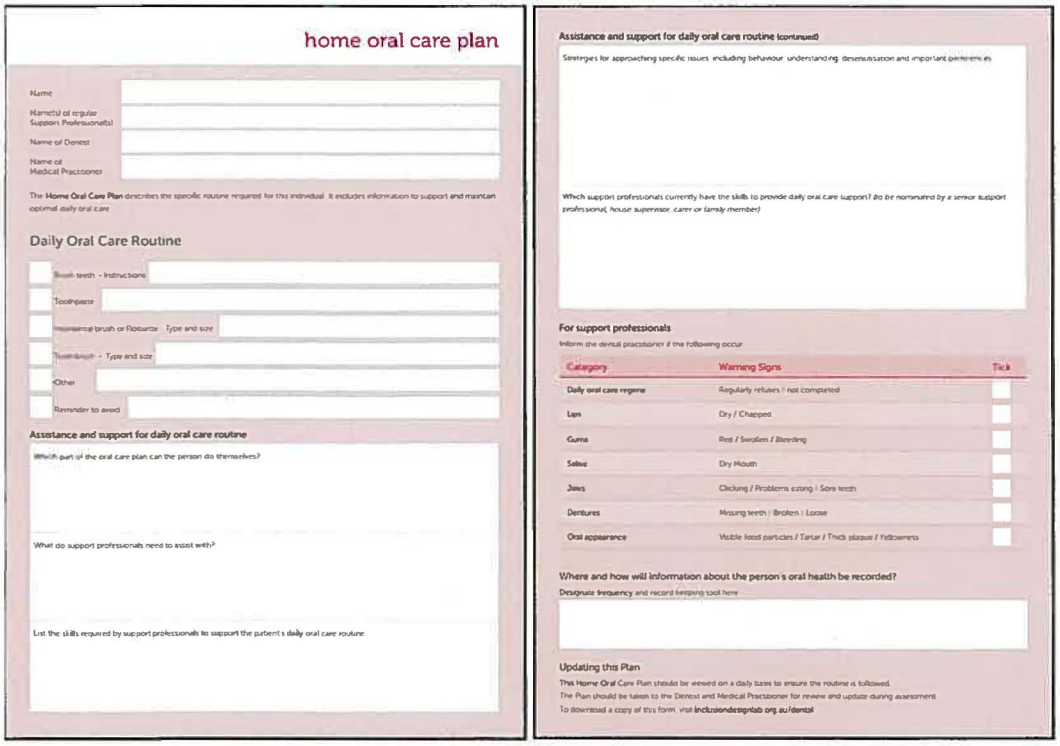
Patient and support professional have been reminded to bring Home Oral Care Plan to all appointments.

A copy of this form has been provided to

Medical Practitioner (as listed at the top of this form)

Support Professional / patient. Please write name below

To download a copy of this form visit inclusiondesignlab.org.au/dental


home oral care plan

Name

Name(s) of regular Support Professional(s)

Name of Dentist

Name of Medical Practitioner

The **Home Oral Care Plan** describes the specific routine required for this individual. It includes information to support and maintain optimal daily oral care

Daily Oral Care Routine

Brush teeth - Instructions

Toothpaste

Interdental brush or Flossette - Type and size

Toothbrush - Type and size

Other

Reminder to assist

Assistance and support for daily oral care routine

Which part of the oral care plan can the person do themselves?

What do support professionals need to assist with?

List the skills required by support professionals to support the patient's daily oral care routine

Assistance and support for daily oral care routine (continued)

Strategies for approaching specific issues including behaviour understanding, desensitisation and important preferences

Which support professionals currently have the skills to provide daily oral care support? (to be nominated by a senior support professional, house supervisor, carer or family member)

For support professionals

Inform the dental practitioner if the following occur

Category	Warning Signs	Tick
Daily oral care regime	Regularly refuses / not completed	
Lips	Dry / Chapped	
Gums	Red / Swollen / Bleeding	
Saliva	Dry Mouth	
Jaws	Clicking / Problems eating / Sore teeth	
Dentures	Missing teeth / Broken / Loose	
Oral appearance	Visible food particles / Tartar / Thick plaque / Yellowness	

Where and how will information about the person's oral health be recorded?

Designate frequency and record keeping tool here

Updating this Plan

This Home Oral Care Plan should be viewed on a daily basis to ensure the routine is followed.

The Plan should be taken to the Dentist and Medical Practitioner for review and update during assessment.

To download a copy of this form, visit inclusiondesignlab.org.au/dental

Dental assessment records should be separated from daily 'progress notes' in the person's files as these are often difficult to search and are regularly overlooked or archived.

h. Oral care for victim/survivors of abuse

Dental practitioners can be key observers of overall health and wellbeing (including abuse prevention) for people with intellectual disability.

However, dental treatment can be difficult for people with post-traumatic stress disorder (PTSD) arising from physical or sexual abuse or past dental/medical interventions. People with a history of sexual abuse often avoid treatment and general care. Many programs for victim/survivors are not accessible to people with disability.

There are confounding issues which can mask identification of people who have PTSD. These include people with physical disability who may have limited tolerance, postural/seating issues, involuntary movement etc., communication issues, cognitive issues, behavioural issues or sensory issues. All these factors make it difficult to assess why a person may refuse or not cope with dental care, either on a daily basis or during professional visits. Some factors may be identified but others may be missed. Abuse may not always be reported, and some people will have difficulty communicating with others what has happened to them. Therefore, it is important for such patients to be able to access care from the same clinician to build rapport and trust.

i. Guardianship

Various types of guardianship and powers of attorney exist throughout Australia, and legislation varies between states. Financial, medical decision maker and legal powers must usually be gained through separate processes. In the past, parents of people with profound intellectual disability have often acted in a de facto guardian capacity for their loved ones, however this is no longer appropriate. The following issues must be considered:

- *Supported Decision Making* is a series of practice models that are gaining increased recognition in the disability support sector as well as other sectors, including legal and medical practice. Supported Decision Making empowers people to make their own decisions to the maximum extent possible and to have these decisions recognised in law. It champions the power of consistent relationships, progressive exposure to new options, continuity of support, and related concepts *in preference to* 'substitute decision making'.
- The Australian Law Reform Commission has called for current guardianship and related substitute decision making mechanisms to be replaced by *Supported Decision Making*. These reforms are now reflected in the National Disability Insurance Agency Act (2013) and state legislation across Australia (e.g. Powers of Attorney Act [Vic] 2014; Mental Health Act [Vic] 2014; Medical Treatment Planning & Decisions Act [Vic] 2016; and Guardianship & Administration Act [Vic] 2019).
- The NDIS allows participants to have a Plan Nominee and/or Communication Nominee. A detailed description of these roles is outside the scope of this submission, however it must be noted that being a Nominee in relation to a person's support funding does not equate to legal guardianship.
- A key implication of Supported Decision Making is that some people with disability will be able to actively engage in their treatment and treatment planning if they are well supported, while some people may be deemed as unable to consent or engage if they are not supported according to best practice. These issues need to be explored and applied in the context of oral health care. Subsequently, dental professionals and disability professionals need to come together to plan a way forward.

j. Referrals

The settings for dental treatment depend on what services are available, what training staff have, and what funding is available. This varies from state to state, and clinic to clinic.

In some areas of the country, there are longstanding SND services, with experienced staff and good processes for treating people with disabilities, and for deciding who is seen in general dental service streams, and who needs more specialised care. The distribution of SND specialists and experienced dentists is uneven throughout Australia and mainly focused in metropolitan centres. This means that there are some parts of the country where suitable services and resources are lacking and the full range of services is not available or is severely restricted.

In areas with established SND services, it is very common for dentists working with a person with intellectual disability and related communication barriers to refer them to oral health professionals in other settings should they feel the patient is unable to consent to treatment, communicate clearly, make decisions, tolerate treatment, or behave in a way that enables treatment. People with ID are frequently referred to Specialists in Special Needs Dentistry and/or the hospital dental services; however, practices vary by region. The proportion of referrals involving people with ID has been reported to range from 4.4% of referrals to Special Care Dentistry units in Tasmania (Lim & Borromeo 2017) to 21% of referrals to the Special Needs Dentistry Unit at the Royal Dental Hospital of Melbourne in Victoria (Rohani et. al. 2017), however data is not available from all states.

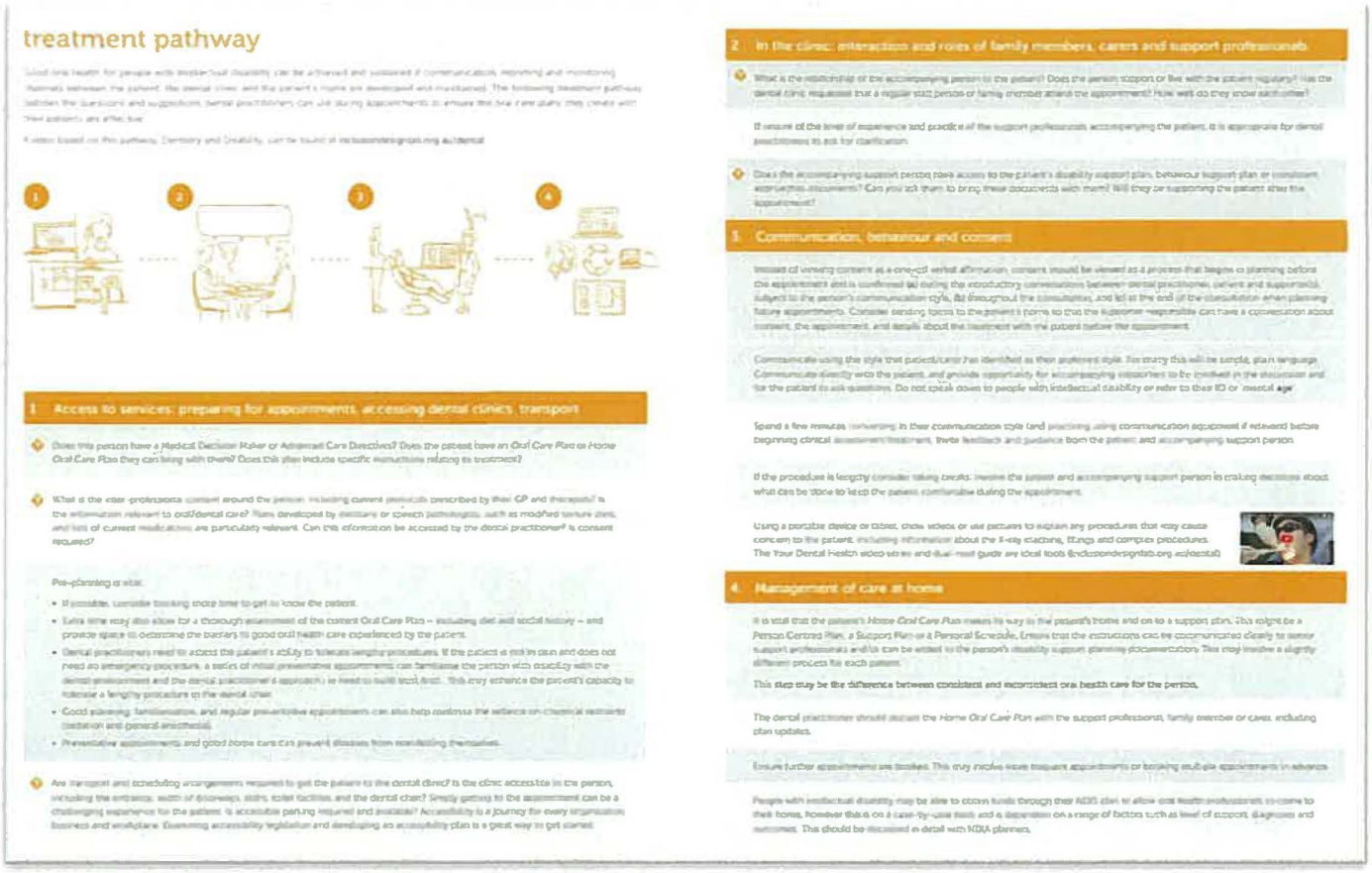
Many people with ID can be seen in general dentistry settings, depending on staff training/experience, adequate processes, suitable facilities, and proficiency in engaging with the relevant disability support systems and inter-disciplinary planning methods. The ability to provide familiarisation and continuity of care with familiar clinical staff and direct support professionals facilitates the provision of regular care, not just episodic relief of pain, and is of utmost importance to enable early identification of oral disease and implementation of early intervention procedures that will reduce the development of advanced oral disease requiring invasive dental treatment under sedation or general anaesthesia for management.

The significant over-referral of people with ID who might otherwise be treated in a general dental setting represents a very real threat to the oral and overall health of Australians with intellectual disability (as well as a significant cost to government!) and represents gaps in practice, collaboration, planning, and interdisciplinary communication – aided by a gap in language and practice knowledge between dentistry and the disability support sector. International referral pathways that triage patient complexity such as the British Case Mix model have been implemented in some states. However overall, there is little in place to prevent this pattern of over-referral, and further training is required in treatment planning and anaesthetic risk assessment for dentists working with patients with ID.

k. Communication

As noted above, the *Oral Health and Intellectual Disability Guide* includes forms for communication between dentists and GPs (see orange form above) and between dentists and disability support professionals (see pink form above). The Guide also provides an overview of a range of communication tools commonly used in the disability support sector, including Active Support plans, Consistent Approaches, and Behaviour Support Plans.

The diagram below is taken from the *Oral Health and Intellectual Disability* Guide (pages 8-9) and outlines a proposed treatment pathway, including communication between dentists, dental administration staff, and disability support professionals.



I. Restrictive Practices

The issue of restrictive practices is a significant one in terms of people's civil and human rights, as well as their access to appropriate health services. It is the opinion of the DOHC and Your Dental Health teams that there is a lack of common understanding and collaboration on this issue between the disability and oral health sectors, leading to gaps in practice and regulation between disability legislation, disability support practice, and health sectors including dentistry.

Across Australia, the use of restrictive practices is carefully regulated by the NDIA Quality and Safeguards Commission and associated state-based oversight bodies. For instance, in Victoria, restrictive practices are monitored and regulated by the Senior Practitioner (Disability), Office of Professional Practice. These include practices such as: chemical restraint, physical restraint, mechanical restraint, and seclusion. The use of consequences and the exercise of power are also identified as restrictive practices by most peak bodies and regulatory authorities. In line with the Disability Act (Vic) 2006, the use of restrictive practices in the delivery of support services to a person with disability must be approved through a regulated process that, in short, involves the application of Positive Behaviour Support (PBS) and a Behaviour Support Plan.

Across Australia, the National Disability Insurance Scheme (NDIS) Quality and Safeguards Commission places increased emphasis on Positive Behaviour Support (PBS) and ensuring that all available strategies are employed so that restrictive practices are minimised and where possible avoided. PBS is a scientifically based intervention that emphasises the importance of both functional and clinical assessment, together with the development of interventions that address environmental, clinical and skills-based issues that contribute to the person's behaviours of concern. While PBS has been evident in the disability sector for many years, it does not currently feature in the education and professional development of most health practitioners.

It should be noted that the actions of direct support professionals fall under the guidelines noted above, including in the dental surgery. This means that dental practitioners cannot ask support professionals to implement restrictive practices such as physical restraint during dental appointments.

Dental practitioners are empowered to use oral anxiolysis or sedation to manage the patient in the least invasive manner should they be unable to treat the person in the dental chair. However, behaviour support strategies require time to implement and there are financial disincentives towards providing such care both in the private dental practice business model and in community dental settings, where practices are subject to waiting lists and productivity targets. This often leads to referrals for treatment under sedation or general anaesthesia.

Good collaboration between the disability support professional and the dental practitioner may lead to alternative approaches, particularly if avoiding the use of sedatives will allow the patient to better express their pain experience and report symptoms.

m. General anaesthesia (GA)

There is concern about people with mild disability being offered treatment under general anaesthetic due to a lack of time and resources and training to manage treatment in less restrictive ways. Equally, there are serious access issues for those patients who do require GA for dental treatment. In some cases, the patient may receive most treatment in the dental chair, but require a GA for certain clinical procedures. In other cases, a GA may be the only way to fully examine a patient and provide necessary treatment.

There are specific issues for those who are victims of abuse and have Post Traumatic Stress Disorder related issues regarding accessing oral health care. There is a lack of services to support people in this situation to access oral health care. Again, treatment under General Anaesthetic needs to be one of a suite of strategies and options to support these individuals.

Funding for treatment under general anaesthesia comes from both state dental funding and federal hospital funding. Some patients are seen through the public system, and some privately. For private patients, health insurance funds are involved in negotiating payments to hospitals. Medicare has a Procedure Banding System, where different procedures are funded differently.

For dental procedures, a low banding rating means that dental procedures attract very little funding for hospitals. The band pays one rate for under one hour, and another for over one hour. There is no provision for increased funding based on the number of types of procedure provided. The nature of dental general anaesthetics is that a typical session may last around two hours, and the patient will undergo multiple procedures. The funding model only works if multiple patients are seen for short procedures.

In addition, most dentists (other than Oralmaxillofacial surgeons) are unable to provide dental treatment under Medicare, further disadvantaging hospitals that offer accreditation and provide regular theatre lists to dentists. This acts as a disincentive for hospitals to accredit and provide regular lists for dentists, as the 'business case' is poor and competition for theatre lists is high.

The type of patient who needs a general anaesthetic is one who may be less likely to express if they have oral pain, and whose behaviour may be impacted by undiagnosed, or untreated dental problems. Many public lists for dental general anaesthetics are in the order of 1-2 years long. The problem is even more difficult for medically complex patients who are not suitable for day surgery.

It is even more difficult if one follows best practice and tries to arrange multi-disciplinary treatment under GA, so that patients can have multiple procedures performed at the same time under the same GA. Accreditation and finding suitable list time make this difficult and can result in patients undergoing multiple general anaesthetics unnecessarily.

Regular triaging of pain to prioritise patients is difficult due to both the sheer number of people on these lists, and the inability of many of these patients to articulate what they are feeling. There is often an additional lag in receiving treatment, being assessed and being added to a general anaesthetic list, as this

often relies on direct support professionals or oral health professionals identifying that the patient may have an oral health condition that is causing pain.

6. NDIS and oral health

At present, the National Disability Insurance Agency has indicated that it will not fund dental treatment. The DOHC and Your Dental Health team are aware of participants who have received limited funds for dental treatment in extreme situations, including funds for frequent cleans and home hygienist support.

Some people with disability have oral health needs that are:

- Intrinsically connected to their disability;
- Not covered adequately by the public system due to type or frequency of required treatment;
- In the scope of 'reasonable and necessary'
- Urgent and critical

Furthermore, many people with disability require funds to cover the support costs related to dental treatment, rather than the cost of the dental appointment itself. These include the following NDIS line items:

- Training for carers
- Speech pathology
- Occupational therapists
- Support workers for home care and support at appointments
- Transport to and from appointments
- Physical assessments
- Home hygienist support
  Behaviour support assessment, planning, and intervention related to the oral health treatment. Please refer to pilot projects in Adelaide (Pradhan et al. 2016a, Pradhan et al. 2016b).

These funds would allow many people with disability to access public and community dental services and to have significantly improved home care.

It is the experience of the DOHC and Your Dental Health team that NDIS planners are not aware of the need to ask questions about oral health and related matters and that many lack an understanding of the range of conditions that often have a direct impact on, or are impacted by, oral health and are therefore directly connected to participants' disability, including behaviour support needs related to dental care There is therefore a funding gap between the public dental system and the NDIS that must be addressed. This gap leads to compounded long term outcomes such as poor general health, gum disease, hospital treatment, and resulting behaviours of concern. These outcomes often lead to financial costs in the form of additional paid direct support and therapeutic assessments – both of which are funded by the NDIS – and out-of-pocket treatment costs not covered by the NDIS.

7. Conclusions

Additional recommendations and conclusions from the above analysis include:

- Funding should be sought to form Communities of Practice that bring together oral health, allied health, psychology, and disability practitioners.
- There is a significant gap in practice and regulation at the point of interaction between dentistry and the disability support profession, with many of the frameworks of one profession not interacting with those of the other. This needs to be addressed through improved education, practice training and regulatory adjustments.
- There is a significant health literacy (oral health and disability) gap that needs to be addressed among dental professionals, non-dental health professionals, support workers, carers, and people with disabilities.

- Greater communication is required between general medicine, dentistry, and the disability support profession.
- There is a lack of equity and common standards regarding the appropriate use of general anaesthetic and restrictive interventions in the treatment of people with intellectual disability, behaviours of concern, and communication limitations. Interdisciplinary collaboration as outlined in this submission can reduce the over-referral to general anaesthesia and allow better access to those for whom this modality is required.
- There is a lack of common understanding of issues related to Positive Behaviour Support, Supported Decision Making and consent as it relates to oral health care for people with intellectual disability, which requires education and training interventions among practitioners (both pre-service and in-service).
- Special Needs Dentistry operates in a unique context and must be supported to play a number of roles:
    - Specialists in SND deliver high quality care to patients who are referred to them, however many of these patients could be treated by their local general dentist
    - General dentists should incorporate a range of (though not all) special needs dentistry techniques into their general practice in order to limit over-referral and reduce the burden on the small number of SND specialists in Australia
    - Regardless, more specialists in SND are needed across Australia
    - Although some dentists, including specialists in SND, often work with people with disability, it must not be assumed that they have a full working knowledge of the policies and practices that govern the disability support sector. Similarly, there is limited understanding of dental disease risk factors and management in the medical and disability sectors. Interprofessional education and practice should be encouraged and supported among all sectors – disability, medical, dental, allied.
- The NDIS must broaden its approach to the oral health of Australians with intellectual disability. The NDIS must:
    - Add oral health considerations – including questions relating to participants' capacity, support needs, and access to dental treatment – to the planning script of NDIS planning meetings
    - Include adequate funds in participants' plans to support access to – and maintenance of – oral health, including: training for carers, speech pathologists, occupational therapists, physiotherapists, psychologists, support workers, transport, home hygienist support, and behaviour support practitioners
- Funding mechanisms to support people with disability to access dental services should not only include the possible need for transport and a support worker, but also for the time that both Oral Health and Disability workers need to take to establish effective communication, achieve familiarisation in an oral health setting, work through informed consent, and develop (a) individualised home based oral health care plans and (b) clinical treatment plans that incorporate the wishes of the person as much as is possible.
- Alterations are required to the Medicare Procedure Banding System so that dentists can provide equitable care within realistic timeframes for patients with disability.
- National Oral Health Surveys must facilitate the collection of baseline data in order to measure and address the gap in data on the Oral Health Status of people with a disability.
- Significant policy work must be undertaken at federal, state and territory levels to establish the most appropriate models for managing and supporting Community Dental Clinics so that they can boost their provision of services to people with disability.
- Pathways – and information about those pathways – must be clearly and meaningfully communicated to people with disability so that they are able to access oral health care. See the ADA-endorsed dual-read guide *Your Dental Health* (https://inclusionmelbourne.org.au/wp-content/uploads/2019/04/IM-Dental-Health-Publication-COMPLETE-2.pdf).

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