ORAL HEALTH AND INTELLECTUAL DISABILITY: LEADING THE WAY IN ADVOCACY AND RESOURCE DEVELOPMENT

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Inclusion Melbourne, the Centre for Developmental Disability Health (CDDH, Monash Health) and the Australian Society for Special Care in Dentistry (ASSCID), along with individuals from across the allied health sector have recently developed the ***Oral Health and Intellectual Disability Guide.*** This Guide outlines key protocols and recommendations for family members, health professionals and support workers to use in achieving optimal oral health outcomes for people with an intellectual disability and had been endorsed by the Australian Dental Association (ADA).

The ***Your Dental Health*** team through their work in producing this guide have highlighted that interdisciplinary collaboration combined with a modest amount of disability knowledge are key components in removing barriers and improving oral health outcomes for people with an intellectual disability.

The team's work also led to a collaborative project with the Disability and Oral Health Collaboration, an interdisciplinary community instigated by Deakin University.

The Your Dental Health project's work now includes articles in the Victorian and Federal editions of the Australian Dental Association's journals, a feature in the Bite Magazine for Australian dentists, and an interview in the Dental Tribune. The project's key publications include:

Your Dental Health:
A Guide for People with a Disability, their Family Carers, Friends and Advocates

Oral Health and Intellectual Disability:
A Guide for Dental Practitioners.

Your Dental Health website:
An online resource containing the above publications and a suite of videos, including short videos that can be shown to people with disability before treatment to aid familiarisation and desensitisation, autism-friendly animations, and a pathway video produced in partnership with Monash Health for dentists illustrating the ways in which they can work collaboratively with disability support professionals during treatment planning.

The focal point of the Your Dental Health project is the treatment pathway, available on pages 8-9 of *Oral Health and Intellectual Disability* (2019). The pathway promotes interaction at each point of the journey, from preparation and appointment planning, through to familiarisation, in-chair treatment, and post-treatment home care. This interdisciplinary pathway acknowledges the skills of well-trained direct support workers, rules relating to restrictive practices, the systems that exist in most group homes, the potential of general dentists, and the power of simple but effective post-treatment planning.

The Your Dental Health's collaboration with the Disability and Oral Health Collaboration saw the production of a joint submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. This unprecedented joint project of Deakin University, University of Melbourne, the Australian Society of Special Care in Dentistry, the Australian and New Zealand Academy of Special Needs Dentistry, the Australian Academy of Paediatric Dentistry, and Inclusion Melbourne resulted in a joint meeting with two Royal Commissioners and a summons to provide evidence to the Commission's Health hearing on Monday 24 February 2020.

The submission focused on the theoretical and practice gaps that exist between dentistry and the disability sector. The following items (listed under the heading 'Gaps' in the Submission) are particularly relevant to the interaction of dentistry and disability support practice. The following is taken directly from the joint Submission:

1. 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.

2. 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.

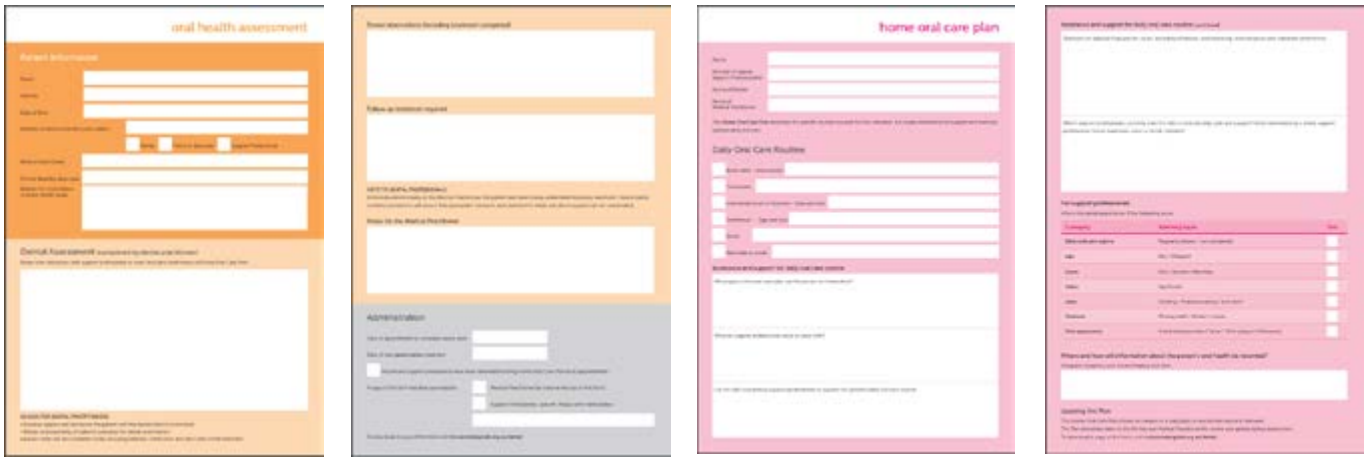
3. Rather than problematising poor oral health as the fault of the individual, a focus on the broader systemic gaps across the oral health and disability sectors is needed. The practices, systems and tools required to support people with intellectual disability to have good oral health – regardless of 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.

4. 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:

    - (a) Between people with intellectual disability and their dentist
    - (b) Between people with intellectual disability and their GP
    - (c) Between supporters and people with intellectual disability
    - (d) Between dentists and GPs
    - (e) Between dentists and supporters, particularly accommodation staff and families
    - (f) 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:



Conclusions from the joint submission to the Royal Commission are reproduced below:

- 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… 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 (SND) 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, and allied health.
- 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.
- 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.

In addition to these conclusions, the Your Dental Health team is working to see:

- An increase in the volume of Special Need Dentistry specialists, as well as better access pathways for people with a disability urgently requiring these specialists, while ensuring that people who could be treated by a general dentist are not over-referred to specialists.
- Suitable upskilling of general dentists in both private and public settings to provide dental care to people with a disability without the need for specialist referral.
- Increased access to General Anaesthetic for those people with a disability requiring treatment that can only be performed under anaesthetic, while ensuring that people who can be treated in a general dental clinic are not over-referred, particularly if PBS can be employed to prevent the need for what is essentially a chemical restraint.
- NDIS funded training for home care (eg. Oral Health Therapists training support workers in group homes), supports pre- and post- dental appointments, and all consumables and devices required for preventative home dental care.

- NDIS funding not only for Speech Pathologists and Occupational Therapists, but also for Oral Health Therapists that can assist with the daily oral care that is so vital for optimal oral health.
- Training for the disability workforce so that support professionals can be aware of basic oral health problems such as red, swollen or bleeding gums, how to engage in basic planning, booking and structuring of dental appointments, recording notes and future appointments in the administrative systems of accommodation providers, and how to communicate relevant oral health information to relevant family members and key support staff.

Such is the prevalence of poor oral health among people with intellectual disability that myths of inevitability and comorbidity are often assumed in the disability sector. However, “enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being” (WHO 1948). So with this in mind, the Your Dental Health team, along with the Disability Oral Health Collaboration and ASSCID, hope that initiatives such as the Oral Health and Intellectual Disability guide along with the joint submission to the Royal Commission will generate significant change in the standard of oral health that is accepted in this population. Poor oral health in people with intellectual disability should not be considered as inevitable, but rather seen as representative of a barrier to the realisation of human rights and quality of life – a barrier that can be easily removed through systems improvements, practice change, and interdisciplinary collaboration.

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