GEELONG PARENT NETWORK

SUBMISSION TO SELECT COMMITTEE INTO THE PROVISION OF AND ACCESS TO DENTAL SERVICES IN AUSTRALIA

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About the Geelong Parent Network

Geelong Parent Network is made up of members who are lifelong family carers of people with intellectual disabilities in the Geelong Region. The Network was an initiative of VALiD (Victorian Advocacy for Individuals with Disability) in 2003 to provide a forum, support and voice for family carers. Most persons being cared for have an intellectual disability of some form and often other disabilities as well. They receive services from a wide variety of disability and community agencies throughout the Geelong region.

Introduction

We know that "Oral health is central to overall wellbeing." And "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." (Department of Health, 2021, 22) With most members of Geelong Parent Network being in their senior years, we also have too often seen 'healthy' interest in and promises for improving lives of people with intellectual disability become short lived. Recent Australian research (e.g. Trollor & Small, 2019) and lobbying that highlighted major inequalities in healthcare and health outcomes for people with intellectual disability has been a catalyst for Federal Government initiatives that include dentistry. We strongly support much greater access to mainstreamed dental services but done differently with 'reasonable adjustments' so that people with intellectual disability do receive the same outcomes as everybody else. "Oral health is central to overall wellbeing" is the preface to initiatives for how oral health outcomes are intended to be linked to such wellbeing under a *National Roadmap for Improving the Health of People with Intellectual Disability*. This submission focuses on 3 of the Select Committee's Terms of Reference (TOR a, g and h).

1. Experience in accessing and affording dental and related services (TOR a)

We know that accessing dental services for many people is in times of crisis. This is a health issue for the general population and certainly for people with a disability. Affordability is only one element. Others include a history of being seen as requiring separate and 'special' treatment and these being metropolitan based, lack of training to provide reasonably adjusted treatments, and poor communication skills. So people with a disability

- experience substantially more oral health problems that impact their overall health than people without disabilities; they receive reduced oral health care that is often of a lower quality (Dental Health Services Victoria, 2008, 1)
- see a GP annually at rate of 92 percent but only see a dental professional at a rate of 51 percent. This rate drops to 46 percent for those aged 25-64yrs. (Australian Institute of Health and Welfare, 2022, 101)

A big issue then is access to dental services and supports that minimise need for access in crises.

Geelong Parent Network has maintained strong connections with dental professionals since 2011. Themes from 2011 meetings were:

- Importance of dentist-patient relationship
- Need for accessible and ongoing understanding advice and support
- Commonly people with intellectual disability cannot/won't wear dentures
- Hospitalisation commonly required for routine dental procedures
- Systemic disincentives for maintenance support – including health insurance and Medicare
- Attitude of dentists to 'cosmetic' procedures
- Metropolitan-centric special dentistry seen as inadequate and often unhelpful to regional needs
- Medication and mouth breathing issues
- Lifelong parent carers confronted with huge challenges in meeting oral health needs in maintenance at home and in accessing professional support.

These themes have continued. Having lifelong dental supports that are proactive with focus on prevention and integration with general health and wellbeing are still largely visionary.

Our journey and experience of dental services have included a dentist prematurely recommending mass extractions and a dentist advising that an implant replacing a front tooth was not worth doing because of a person's disability. But we have also experienced dentists working with hospital staff and anaesthetists. They worked together. They listened and even made sure a hand was held. They made 'reasonable adjustments' to their operating routines such as shortened pre-op arrangements, allowing the parent carer to accompany a person into the operating theatre till going to sleep and be by their side when waking.

We know the *National Disability Strategy 2010-2020* highlighted that: "Life expectancy may be up to 20 years lower for people with a severe intellectual disability than the general population (p.60). It added that a significant factor to this statistic was that "Dental disease is up to seven times more common than in the general population." (p.60) The *National Roadmap for Improving the Health of People with Intellectual Disability* stated that compared with the general population, people with intellectual disability experience:

- 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;
- significantly lower rates of preventative healthcare. (p.v)

We know that people with an intellectual disability have additional risks for developing oral health problems (Department of Human Services, 2009, Section 5.10). This can be related to

- their ability for competent, regular oral hygiene practice;
- lack of normal swallowing and eating functions, such as reduced ability to clear food from the mouth resulting in food remaining in the mouth and cheeks for long periods;
- tooth grinding, medicines, and saliva production also greatly affecting oral health and oral hygiene practices.

Some people with intellectual disability cannot verbally communicate their pain with much accuracy. The communication may be expressed verbally but without much help to a diagnosis and it may be expressed nonverbally through behaviours. This makes the need for preventive dentistry more vital, as for example through annual assessments and plan maintenance particularly when linked to general health assessments.

We live the experience of facing a wide range of medical, social, economic, educational and cultural challenges. It should be no surprise then that unless there is an immediate crisis, seeking dental service may be treated as a lower priority than it should. It does not help that many dental professionals have had too little understanding or training. Special dental services being metropolitan based and overwhelmed by largely crisis conditions have too often been unsatisfactory to our members.

There are daily challenges for many carers in supporting both children and adults too in teeth brushing and cleaning twice a day. This is a lifetime motivational or physical support for many adults with more severe intellectual disability. Members found helpful a guide for carers of adults with disability titled *How to Brush Someone Else's Teeth* authored by Centre for Oral Health Strategy. Also helpful was Inclusiondesignlab's comprehensive guide, *Your Dental Health,* for people with a disability, family carers, friends and advocates. While there are supports that get to carers of people with intellectual disability living in residential services, there are too few supports get to the much greater numbers of people who continue to live with their families.

2. Pathways to improve oral health outcomes (TOR g)

Pathways to what? Yes, to 'improved' oral health outcomes that include 'universal access'. Geelong Parent Network sees 'improved' as needing to recognise the impoverished position of people with intellectual disability whose history has been one of "reduced oral health care that is often of a lower quality." (Dental Health Services Victoria, 2008, 1) Given that "Oral health is central to overall wellbeing." (Department of Health, 2021, 22), poor oral healthcare is likely to have been a significant factor in their much reduced life expectancy. 'Improvement' must necessarily address preventive and integrated healthcare and 'universal' must address reasonable mainstream access. There are some positive signs for these, but from the perspective of many lifetime parent carers of people with intellectual disability who have seen so many initiatives on their journeys dry up, these are 'baby steps'. The *National Roadmap for Improving the Health of People with Intellectual Disability* across all of its elements and initiatives recognises the need for preventive and integrated healthcare that would be universal. An example we propose relates to 'tweaking' an MBS item. The *National Roadmap* proposes to "Implement measures to better promote the use of annual health assessments and other relevant MBS items to people with intellectual disability, their families, carers and support workers." (p.4) In doing this it expects to "Review and consider potential modifications to MBS items for people with intellectual disability." (p.4) There are four time-based MBS health assessment items: 701 (brief), 703 (standard), 705 (long) and 707 (prolonged) that are pertinent. These are for health assessments by a medical practitioner (other than a specialist or consultant physician) that include being for people with an intellectual disability. The decision to use any one of these four MBS health assessment items to carry out a health assessment depends on the practitioner's clinical judgement based on the complexity of the presentation and the type of health assessment used. (Department of Health and Ageing, 2023) Geelong Parent Network proposes that the 'usual' medical practitioner be able within these MBS health assessment items to arrange for a dental health assessment, with a copy of the assessment record to be forwarded to the patient's 'usual doctor' or practice, subject to agreement of the patient or their parent/guardian. Adopting this would provide for a more holistic assessment than does current practice, and be consistent with National Roadmap goals for preventive and integrated healthcare in mainstream settings.

An effect of crisis driven access to dental services is lack of ongoing care planning. Individualized oral health care plans developed between the person with intellectual disability, their families and carers and their dentist would greatly assist improved oral and general health. Long recommended but little practised, such plans might include:

- Description of person's abilities to participate in their oral care routine, for example, what can they do for themselves?
- Environmental set-up (including tools and product, positioning and physical set-up of environment)
- Timing and daily routine
- Communication approaches
- Specific management approaches where appropriate to overcome behaviour and cognitive issues. (Department of Human Services, 2009, 11)

The plan should be helpful in ensuring consistency if the person is in respite. It might also be part of a Day Program plan if appropriate as well as being supported at home with family members.

Oral Health and Intellectual Disability (Inclusiondesignlab, 2019) is a guide for dental practitioners that includes a treatment pathway intended to support "most patients with mild or moderate disability (being) treated successfully in the general dental clinic." The treatment pathway is based on promoting effective communication, reporting and monitoring and incorporates questions and suggestions for dental practitioners to use during appointments.

1. Access to services: preparing for appointments, accessing dental clinics, transport
2. In the clinic: interaction and roles of family members, carers and support professionals
3. Communication, behaviour and consent
4. Management of care at home.

3. Adequacy of data collection (TOR h)

In the Consultation period in 2014 for drafting a new National Oral Health Plan, Geelong Parent Network's submission included the following in relation to data collection:

> It is of concern that "People with disabilities is the only priority area of the National Oral Health Plan which has no population based data collected for it." (NOHP website) The situation is exacerbated for people with intellectual disability/impaired decision-making where the impact of their disability is likely to be more profound (cf. *National Disability Strategy 2010-2020*, 60). … without a major focus with commensurate intensity (referring to Marmot's 'proportionate universalism'), the lack of appropriate population data bases will only ensure (their) continuing 'invisibility'.

The only response was silence. The following 10 year plan made no reference to what the National Disability Strategy had highlighted.

The *National Oral Health Plan 2015-2024* (COAG Health Council, 2015) placed people with disabilities among a range of groups classified as Priority Population 4 - People with additional and/or specialised health care needs. In its two paragraph description of people with disabilities, it noted: "While there is no national oral health data on people with disabilities, and only very limited state-level data on specific disability groups, current indications are that people with disabilities suffer from poorer oral health than the general population." (p.64) There was no reference to the *National Disability Strategy 2010-2020* that had highlighted the plight of people with intellectual disability: "Life expectancy may be up to 20 years lower for people with a severe intellectual disability than the general population … Dental disease is up to seven times more common than in the general population." (p.60) The *National Oral Health Plan 2015-2024* did however refer to a 2009 study of people with disability accessing dental services. The nature of the disability was not identified in the and was only apparent from the title in the reference list. The quote: "A lack of dentists with adequate skills in Special Needs Dentistry was the most frequently reported problem for carers from family homes and community houses, followed by a lack of dentists willing to treat people with disabilities, resulting in long waiting lists. Carers from family homes and community houses were more likely to report problems in obtaining dental care than those at institutions." (p.63) The Plan identified that 'dentists had a problem' and 'carers had a problem'. It did not reference the *National Disability Strategy* 2010-20 and it did not recognise the impact on the lives of many people with intellectual disability and their families. It is interesting to note the first recommendation of the authors of the 2009 study: "Based on this study, we recommend programmes to address equity" (p.210) And, more than a decade later, people with intellectual disability, their families and carers are looking for just that: equity.

The Geelong Parent Network has been active since 2019-20 in lobbying the Australian Government for health equity for people with intellectual disability. It then participated in the development of the National Roadmap throughout Roundtable discussions in 2021-22, particularly in inclusion of Oral Health. The Australian Government is currently establishing a National Centre of Excellence in Intellectual Disability Health (Department of Health and Ageing, 2023). Among its core functions is "supporting intellectual disability health … by identifying national research and data priorities to inform practice, and advising research bodies on these priorities; translating research generated by others; and analysing and interpreting health data to improve the health of people with intellectual disability". (p.6) Its objectives include "better use of research and data to inform practice and improve the health of people with intellectual disability." (p.7) The Guidelines also state that one of the performance indicators against which it will be measure is that "People with intellectual disability are meaningfully included in the governance structure and staffing of the National Centre." (p.8)

Conclusion

Members of the Disability and Oral Health Collaboration (DOHC) met with Commissioners from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in August 2019. Geelong Parent Network strongly supports the submission made by DOHC to the Commission. The DOHC submission states that for people with intellectual disability "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." We acknowledge this critical role that our families have in dental health of our daughters and sons. We look forward to much improved supports that recognise "disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (United Nations, 2006, 1)

References

Australian Institute of Health and Welfare. *People with disability in Australia 2022.* Canberra: AIHW, Australian Government, 2022. (Catalogue number DIS 72)

Centre for Oral Health Strategy. *How to brush someone else's teeth*. NSW Health, 2022. Available at https://www.health.nsw.gov.au/oralhealth/prevention/Publications/special-needs-adult.pdf (Accessed 4 February 2023)

COAG Health Council. *Healthy mouths, healthy lives: Australia's National Oral Health Plan 2015–2024*. Adelaide: South Australian Dental Service. 2015.

Dental Health Services Victoria. *Oral health information for people with an intellectual disability*. Melbourne, 2008

Department of Health. *National Roadmap for Improving the Health of People with Intellectual D*isability, Canberra: 2021.

Department of Health and Aged Care. *MBS Health Assessments Items 701, 703, 705, 707 and 715.* Australian Government. Available at https://www1.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare_mbsitem_general_factsheet (Accessed 13 April 2023)

Department of Health and Aged Care. *National Centre of Excellence in Intellectual Disability Health Grant Opportunity Guidelines*. Australian Government, 2023.

Department of Human Services. *Residential Services Practice Manual*, 2nd ed. Melbourne: Disability Services Division, 2009.

Department of Social Services. *National Disability Strategy 2010-2020.* Canberra: Commonwealth of Australia, 2011

Inclusiondesignlab. *Oral health and intellectual Disability.* Melbourne, 2019. Available at https://inclusionmelbourne.org.au/wp-content/uploads/2019/05/Oral-health-and-disability-web-spreads.pdf (Accessed 13 April 2023)

Inclusiondesignlab. *Your dental health.* Melbourne. Undated. Available at https://inclusionmelbourne.org.au/wp-content/uploads/2019/04/IM-Dental-Health-Publication-COMPLETE-2.pdf (Accessed 16 February 2021)

Pradhan A, Slade G, Spencer A. *Access to dental care among adults with physical and intellectual disabilities: residence factors.* Australian Dental Journal, 2009; 54: 204-11.

Trollor, J. & Small, J. *Health Inequality and People with Intellectual Disability – Research* Summary. Faculty of Medicine, The Department of Developmental Disability Neuropsychiatry, UNSW: Sydney, 2019.

United Nations. *Convention on the Rights of Persons with Disabilities and Optional Protocol.* 2006. Available at https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf (Accessed 13 April 2023)