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# oral health & disability in children

a guide for oral  
health practitioners





## oral health is central to good overall health

Good oral health is required if children and young people are to:

- ▶ experience good overall health and wellbeing
- ▶ grow and develop into healthy adults
- ▶ function to the best of their abilities

However, children and young people with disability are at increased risk of poor oral health and face multiple barriers to accessing dental services.

This guide is for dentists, dental therapists, oral health therapists, dental hygienists and other support professionals. It outlines some of the barriers to good oral health experienced by children and young people with disability. It provides strategies that dental practitioners can use to identify these barriers so that they can engage patients' support networks and provide high quality dental care.

“Oral health is considered integral to general health, with poor oral health likely to exist when general health is poor and vice versa. Oral health refers to the standard of health of the oral and related tissues that enable an individual to eat, speak and socialise without active disease, discomfort or embarrassment. While oral diseases are common, they are largely preventable through population-level interventions (including water fluoridation), and individual practices such as personal oral hygiene and regular preventive dental care.”

(Centre for Oral Health Strategy NSW, 2013:4)

## defining disability

This definition highlights the need for dental practitioners and medical practitioners to address the health issues of children with a disability from the perspective of the patient and their individual needs, rather than focusing on the child's diagnosis or impairments. While diagnosis is important, particularly for children and young people whose specific conditions have associated comorbidities, it must be recognised that the barriers to oral health experienced by most children with intellectual disability relate to social, cognitive, communication, motor, sensory and behavioural factors rather than their formal diagnosis of disability. Indeed for children and young people with intellectual disability, the experience of disability is too often defined by social exclusion and the disadvantage caused by societal assumptions and a lack of support, rather than medical or functional diagnoses.

The dental needs of children with a disability may, in some cases, be greater than other patients in the general community due to the volume of competing pressures (such as other therapeutic interventions and supporting early learning) causing a lack of focus on oral care, particularly self-care. These may be further compounded by social disadvantage or insufficient direct support.

While dental practitioners are familiar with planning both simple and complex treatments, the approach used for treatment planning for a patient with intellectual disability may require modifications such as:

- ▶ Additional attention given to communication, familiarisation, and consent.
- ▶ Creative and efficient solutions to some of the practical barriers experienced by patients. Barriers include heightened anxiety, stretched support networks, infrequent dental care, and procedures that require a series of appointments.

The WHO International Classification of Functioning describes disability as an umbrella term, covering:

- ▶ impairments
- ▶ activity limitations
- ▶ participation restrictions

Disability is diverse and includes those who have a range of impairments with or without additional needs. However not everyone with disability will have complex needs. The scope is broad, covering people with physical, sensory, cognitive, medical, emotional or social impairments, or more often, a combination of these factors.

*(FDI statement on Oral Health and Dental Care of People with Disabilities, 2016)*

Most patients with mild or moderate disability can be treated successfully in the general dental clinic.



## children with intellectual disability may have additional health needs

### + more

- Multiple, chronic, complex medical problems**  
Including epilepsy, vision/hearing impairment, dysphagia, malnutrition, obesity, reflux disease, constipation, skin conditions, and cardiac, endocrine and musculoskeletal disorders.
- Mental health and behaviour support needs**  
Greater risk and fewer resilience factors.
- Unrecognised & under treated health conditions**  
Including physical and mental health.
- Medication**  
Side-effects can influence oral health and caries risk.
- Lifestyle risk factors**  
Including nutrition, Vitamin D deficiency, exercise and socioeconomic disadvantage.
- Communication difficulties**

### - less

- Financial resources**  
Parents and caregivers may be unable to work due to caring for children with intellectual disability.
- Health education/promotion**  
More barriers to exercise and healthy eating.
- Preventive healthcare & diagnostic screening**  
Difficulties in getting timely appointments and assessment.
- Social networks, participation, social connection**

### lifespan

- Potentially avoidable death:**
  - ▶ Occurs 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., 2017)
  - ▶ More than a third of deaths potentially amenable to health care interventions (UK: Hosking et al., 2016).
- Lower life expectancy found in global research:**
  - ▶ 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 of 27 years between people with intellectual disability and the general population (NSW: Trollor et al., 2017)

## achieving better outcomes

Achieving better outcomes for children with disability requires moving beyond a focus on diagnoses or interactions in appointments to an expanded focus on support, relationships with families, and planning with other health professionals. These can be simplified into two categories: collaboration and communication.

While there are some dental conditions specific to particular impairments or diagnoses (discussed later), the key challenge for the dental practitioner lies in addressing the support and psycho-social needs of patients.

### 1. collaboration

Collaborating effectively with parents/caregivers, families, health providers (including general practitioners, specialists, dietitians, speech pathologists, oral health therapists, and occupational therapists), and key support professionals (including social workers and case managers) is essential to ensure optimum health outcomes and completion of home oral care plans, as well as facilitating the early identification of oral disease.

Most children may be under the care of their family/caregiver however many families may have support workers and additional support.

It is important to ensure dental advice goes home with the family and can be incorporated into an oral health plan that all carers have access to, particularly advice about serious oral health concerns, treatment, and home care.

### 2. communication

Some children with intellectual disability communicate verbally and in ways that are similar to or the same as any other child. However some children do not or can not speak, while others can do so with limited speech. Some children may have different ways of communicating altogether and in these cases alternative methods of communication may be required. This is known as 'complex communication' and is different for each person. It is important to take the time to communicate directly with the child and build a relationship that will result in good rapport. It is essential to spend time discussing how the child best communicates with the parent/caregiver prior to commencing any treatment. There are a number of aspects to good communication, especially in children with complex communication needs:

- a. **Use of communication techniques with patients who have communication barriers.** This may necessitate the dental practitioner using techniques such as Tell, Show, Do, providing breaks and reassurance, giving extra time for responses, and desensitisation.

- b. **Communication with parents/caregivers/key support workers.** Parents/caregivers may be tired or stressed and may have experienced difficulties prior to the dental appointment. Clear explanations, printed, written or emailed information and guidance can be useful when there is a need to work with other health professionals. Good communication with the child's family will often result in better outcomes.
- c. **Recognising that what is often referred to as behaviours of concern or challenging behaviour is better viewed through the lens of communication.** A complete outline of the links between communication and behaviour is outside the scope of this guide. However, in summary, it can be said that most challenging behaviour is a way of communicating concerns or issues that the person is experiencing.

Tips or guidelines for communication will often be available in the person's **Support Plan, Behaviour Support Plan,** or similar documents. You can ask the child's parent or caregiver for a copy of relevant documents if appropriate.

Significant steps have been taken by Australian governments and disability advocates in recent years to reduce the use of restrictive practices in the lives of people with intellectual disability.

Restrictive practices are defined by the NDIS Commission as mechanical, physical, chemical, environmental restraints, and seclusion.

Improved collaboration and communication have the power to reduce 'behaviours of concern' in many people with intellectual disability, thus avoiding the need for restrictive practices - both in the community and in healthcare settings.

For more information about Positive Behaviour Support, Behaviour Support Plans, Support Plans, and Restrictive Practice, visit: [www.ndiscommission.gov.au/providers/behaviour-support](http://www.ndiscommission.gov.au/providers/behaviour-support)

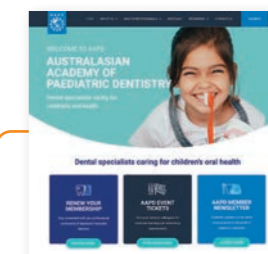
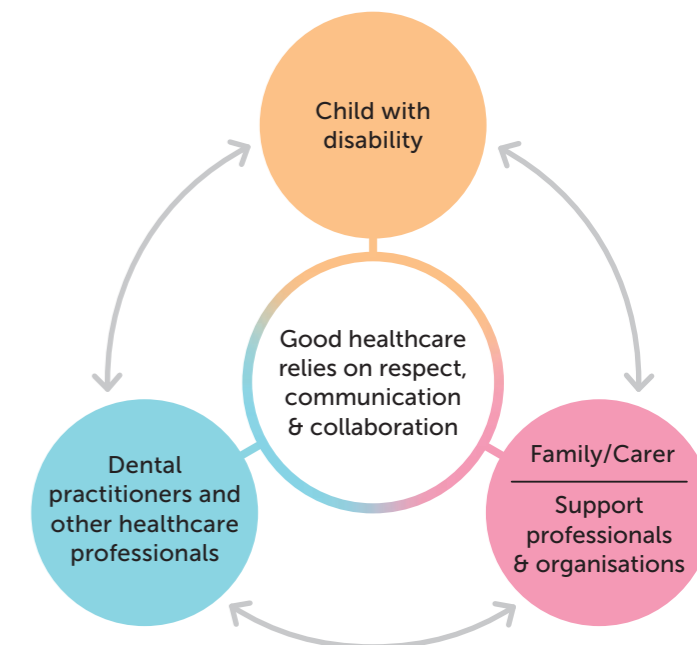
## working in partnership

A majority of children with intellectual disability live with their family, however some live in supported accommodation. Both may have the involvement of disability support workers including family support, respite, recreation groups, day programs, specialist schools, case management and behaviour support. It is important to remember many of these professionals have little oral health training or knowledge.

Disability support professionals work according to diverse schedules and organisational structures. Some are long-term practitioners with significant experience in health planning. Others are minimally trained casual staff.

Good oral care can be achieved by ensuring effective collaboration and communication between all parties, including documenting assessment, treatment and daily oral care. Taking some time to understand the knowledge of oral health and your patient that support professionals and carers (including parents) have, can aid effective collaboration.

There are helpful planning forms at the end of this guide or visit [inclusiondesignlab.org.au/dental](http://inclusiondesignlab.org.au/dental).



For information, resources, and directories to specialist paediatric dental services, visit: [www.aapd.org.au](http://www.aapd.org.au)



For videos, animations, and the ADA-endorsed dual-read publication *Your Dental Health*, visit: [inclusiondesignlab.org.au/dental](http://inclusiondesignlab.org.au/dental)

## what should the dental practitioner do?

- ▶ Use clear language and avoid jargon when communicating with patients and their support people.
- ▶ Document summaries of key points in relation to the assessments.
- ▶ Make sure information is recorded and conveyed clearly.
- ▶ Engage with support professionals and parents/caregivers to get an understanding of their level of experience and knowledge of oral health.
- ▶ Provide opportunities to practice the skills recommended in the home oral care plan.
- ▶ Take responsibility for proactive healthcare and regular review to ensure interventions are implemented effectively and in a timely manner.



Document your assessment, treatment and home oral care. Refer to the planning forms at the end of this Guide, **Oral Health Assessment and Home Oral Care Plan**, or visit [inclusiondesignlab.org.au/dental](http://inclusiondesignlab.org.au/dental)

Encourage the dissemination of these documents between all parties.



## bridging the gap between oral and overall health

While poor oral health is a significant health concern in itself, the link between oral and systemic health is also well established in literature. Early intervention has the potential to avoid some of the more risky health outcomes that can appear during later adolescence and adulthood. 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).

Individuals with disability have poorer outcomes including: extractions rather than fillings, increased severity of periodontal disease, and a lack of functional replacement of extracted teeth. (Mac Giolla Phadraig et al., 2014)

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)

For more information about oral health and noncommunicable diseases visit the FDI World Dental Federation: <https://www.fdiworlddental.org/oral-health-and-noncommunicable-diseases>

The following table shows some of the causes, conditions and adverse effects experienced by children and young people with disability.

<b>difficulty chewing</b>	<ul style="list-style-type: none"> <li>▶ Possibly requiring altered duration and frequency of meals</li> <li>▶ Poor or inadequate nutrition</li> <li>▶ Requiring a modified and possibly cariogenic diet</li> </ul>	<ul style="list-style-type: none"> <li>▶ Social awkwardness</li> <li>▶ Potential for choking and aspiration</li> <li>▶ Possibly requiring a nil oral nutritional intake</li> </ul>	
<b>dental decay &amp; tooth loss</b>	<ul style="list-style-type: none"> <li>▶ Impact on speech, appearance, self esteem, eating and language development</li> <li>▶ May cause oral malodour</li> <li>▶ May adversely impact on social inclusion and participation</li> <li>▶ Pain and discomfort</li> <li>▶ Periodontal disease</li> </ul>		
<b>medications</b>	<p>Some medications may cause:</p> <ul style="list-style-type: none"> <li>▶ Gingival hyperplasia</li> <li>▶ Xerostomia</li> <li>▶ Hyposalivation</li> <li>▶ Tooth Staining</li> </ul>	<ul style="list-style-type: none"> <li>▶ Erosion</li> <li>▶ Plaque accumulation</li> <li>▶ Gingival inflammation</li> <li>▶ Low saliva pH, less buffering, and altered consistency</li> </ul>	<ul style="list-style-type: none"> <li>▶ Caries and periodontal disease</li> <li>▶ Soft tissue diseases</li> </ul>
<b>severe caries</b>	<ul style="list-style-type: none"> <li>▶ Necrotic tooth pulp</li> </ul>	<ul style="list-style-type: none"> <li>▶ Pain and distress: Some children may not be able to verbalise their pain and may exhibit self harming behaviours</li> <li>▶ Halitosis, cellulitis, sinusitis, bacteremia</li> </ul>	

Poor oral health in children and young people may lead to complications in adult patients:

<b>Aspiration of oral bacteria in adult patients</b>	<ul style="list-style-type: none"> <li>▶ Aspiration pneumonia</li> <li>▶ Recurrent infection</li> <li>▶ Respiratory diseases: Oral care interventions have led to a 90% reduction in ventilator associated pneumonia (Hutchins et al., 2009).</li> <li>▶ Dry, crusted saliva mixed with mucous from elsewhere in the gastrointestinal tract sitting around mouth and lips</li> </ul>
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## common conditions found in children with intellectual disability

Among dentists who do treat individuals with intellectual and developmental disability, 99% have identified poor oral hygiene as the single greatest threat to their patients. (Binkley et al., 2014)

The following chart outlines some of the common issues experienced by children with a particular diagnosis. Dental practitioners should screen patients for issues common to children with particular conditions. This list does not include all possible conditions or common issues.

<p><b>DIAGNOSIS OR CONDITION</b></p> <p><b>Autism Spectrum Disorder (ASD) and other conditions/syndromes which may have behavioural issues or oral/dental associations e.g. Fragile X, Rett Syndrome, Williams Syndrome, ADHD, Oppositional defiant disorder (ODD), compulsive disorders, dyspraxia, dyslexia, dysphagia</b></p>	<p><b>DIAGNOSIS OR CONDITION</b></p> <p><b>Intellectual Disability</b></p> <p>Sometimes called Learning, Cognitive, or Developmental Disability.</p>
<p><b>COMMON OR OCCASIONAL ISSUES THAT MAY IMPACT ORAL HEALTH</b></p> <ul style="list-style-type: none"> <li>▶ Sensory issues, such as increased or decreased sensitivity to touch, taste, textures, sounds, light, liquids, and temperature</li> <li>▶ Damaging oral habits are common and may include: bruxism, tongue thrusting, self-injurious behaviour such as picking at the gingiva or biting the lips, pica</li> <li>▶ May have limited food selections including variety of foods and textures</li> <li>▶ May have taste and texture aversion to common oral health products, e.g. toothpaste, prophylactic paste, fluoride varnish</li> <li>▶ Difficulty with motor skills or dexterity, brushing, spitting, swallowing</li> <li>▶ Level of co-operation may affect possible modality of completing dental treatment (e.g. sedation, nitrous oxide and general anaesthesia)</li> <li>▶ Communication difficulties</li> <li>▶ Cooperation challenges</li> </ul> <p><b>TIP</b> Positive desensitisation appointment(s) to familiarise the patient with the staff, office and equipment using a step-by-step process are often beneficial for children with ASD.</p>	<p><b>COMMON OR OCCASIONAL ISSUES THAT MAY IMPACT ORAL HEALTH</b></p> <ul style="list-style-type: none"> <li>▶ Difficulty understanding regular child-focused health promotion strategies and the importance of good oral health</li> <li>▶ Difficulty in achieving required dexterity for oral care</li> <li>▶ Families and carers having lower awareness of the importance of oral hygiene practice</li> <li>▶ Reduced ability to understand new information and complex instructions</li> <li>▶ May find routine dental treatment more challenging</li> <li>▶ Reliance on parents and carers to assist them with food selection and daily oral hygiene beyond what might otherwise be expected for other children</li> <li>▶ Medication which may affect gingivae and saliva production, quality and function</li> <li>▶ Oro-motor dysfunction with reduced food clearing and contribution to occlusal issues</li> <li>▶ Communication difficulties</li> </ul> <p><b>TIP</b> Cooperation with oral health treatment may be challenging for people with intellectual disability. Taking breaks and making sure the patient understands what is happening are often beneficial for children with intellectual disability.</p>
<p><b>CLINICAL DENTAL FINDINGS</b></p> <ul style="list-style-type: none"> <li>▶ Some evidence shows a possible increase regarding caries risk</li> <li>▶ Periodontal disease, contributed to by poor daily oral hygiene and medication, occurs in children with autism in much the same way it does in adults without developmental disability</li> <li>▶ Oral habits and low muscle tone may contribute to dental caries and periodontal disease, and malocclusion</li> </ul>	<p><b>CLINICAL DENTAL FINDINGS</b></p> <ul style="list-style-type: none"> <li>▶ Some evidence shows a possible increased caries risk for children with intellectual disability, however due to poor access to appropriate diagnosis and treatment, it is likely that the extent of decay is under-reported</li> <li>▶ Poorer oral hygiene (leading to increased levels of plaque and worse gingival status)</li> <li>▶ Worse periodontal conditions (likely related to poorer oral hygiene)</li> </ul>

## DIAGNOSIS OR CONDITION

## Down Syndrome

## COMMON OR OCCASIONAL ISSUES THAT MAY IMPACT ORAL HEALTH

- ▶ Greater incidence of cardiac anomalies
- ▶ Increased risk of epilepsy or other seizure disorders
- ▶ Fine motor issues e.g. compromised ability to perform effective oral hygiene
- ▶ Increased risk of obstructive sleep apnoea (OSA)
- ▶ Relatively larger tongue mass and forward posturing

## CLINICAL DENTAL FINDINGS

- ▶ Increased risk of periodontitis (neutrophil dysfunction) and gingival overgrowth (anti-epileptic drugs)
- ▶ Over-retention of primary teeth (commonly known as 'baby teeth')
- ▶ Increased incidence of missing teeth
- ▶ Increased incidence of conical/anomalous teeth
- ▶ Higher prevalence of malocclusion
- ▶ Higher prevalence of attrition and tooth wear due to bruxism

## DIAGNOSIS OR CONDITION

## Craniofacial conditions e.g. Cleft lip and palate, Pierre Robin, Velo-Cardio-Facial syndrome (VCFS)

## COMMON OR OCCASIONAL ISSUES THAT MAY IMPACT ORAL HEALTH

- ▶ May have cardiac issues
- ▶ May have seizure issues
- ▶ May have cognitive issues
- ▶ May have speech issues
- ▶ Challenges with eating

## CLINICAL DENTAL FINDINGS

- ▶ Higher chance of malocclusion
- ▶ Structural defects of enamel are more likely to occur in children with multiple developmental conditions
- ▶ Higher incidence of missing/extra teeth

## DIAGNOSIS OR CONDITION

## Cerebral Palsy

## COMMON OR OCCASIONAL ISSUES THAT MAY IMPACT ORAL HEALTH

- ▶ Possibility of oro-motor dysfunction
- ▶ May have dysphagia
- ▶ Lack of normal masticatory function in some children
- ▶ Bruxism (particularly in children with severe motor and cognitive issues)
- ▶ Gastro-oesophageal acid reflux more common
- ▶ Excessive salivation/drooling (sialorrhea)/difficulty swallowing
- ▶ Regurgitation, vomiting and aspiration can result in dental erosion
- ▶ Tactile intolerance
- ▶ Temporomandibular joint (TMJ) dysfunction
- ▶ Motor and coordination difficulties – can affect ability to perform adequate oral hygiene
- ▶ Fine motor issues that compromise the ability to clean teeth effectively
- ▶ Communication difficulties
- ▶ Cooperation challenges
- ▶ Special seating and positioning adjustment may be required

## CLINICAL DENTAL FINDINGS

- ▶ Structural defects of enamel are more likely to occur in children with multiple developmental conditions
- ▶ Gingival hyperplasia (can be related to difficulties in oral hygiene, intraoral sensitivity, oro-facial motor dysfunction, anti-epileptic drugs)
- ▶ Erosion and tooth wear (due to GORD and bruxism) with associated pulpal risk and tooth sensitivity
- ▶ Higher prevalence of malocclusion (including anterior open bite and overjet)
- ▶ Dental trauma (linked with prominent maxillary incisors and incompetent lips as well as motor deficits)

Dental practitioners should remember that children and young people with disability often have a wide range of complex issues, many of which could impact their oral health care. These include:



Financial considerations that may necessitate choice between oral care and other systematic care.



Care providers being overwhelmed with the burden of complex medical care and day to day care at the expense of prioritising oral health. Dental practitioners may not be able to alleviate these burdens directly, however recognising that such stressors exist may enhance communication and understanding.



Oral health problems failing to be recognised, discussed or considered by medical or other allied health practitioners. Interdisciplinary care teams may not be available for all children or young people with disability.



Medical treatment requiring the intake of medications, modified diets or alternative feeding methods that may also increase the risk of decay in children and young people with disability.



Motor/Movement conditions such as cerebral palsy. These conditions may contribute to access barriers and limitations to adequate oral care regimens. They are more common in the population treated by paediatric dentists.



## treatment pathway

Good oral health for children and young people with disability can be achieved and sustained if communication, reporting and monitoring channels between the patient, their family/caregivers, the dental clinic and other medical and allied health professionals are developed and maintained. The following treatment pathway outlines the questions and suggestions dental practitioners can use during appointments to ensure the oral care plans they create with their patients are effective.

A video based on this pathway, Dentistry and Disability, can be found at [inclusiondesignlab.org.au/dental](http://inclusiondesignlab.org.au/dental).



1 Access to services: Preparing for appointments, accessing dental clinics, transport	
A	Who is the main carer or person that provides consent for this child (parent, caregiver, caseworker/case manager)? Does the patient have an Oral Care Plan or Home Oral Care Plan they can bring with them? Does this plan include specific instructions relating to treatment? Can they provide consent for additional dental care if required?
B	Does the child have any other protocols prescribed by their GP, specialist or allied health care providers (e.g. Dietitian, Speech Pathologist, Physiotherapist, Occupational Therapist) that may be relevant to oral/dental care? For example, modified texture diets, current medications, modified tooth brush, oral care devices. Are these documented clearly and can these be accessed by the dental practitioner?
C	<p><b>Pre-planning is vital.</b></p> <ul style="list-style-type: none"> <li>i. Consider arranging a longer appointment to get to know the child. If possible, schedule time for the patient to explore the space without treatment in the days before their first treatment.</li> <li>ii. If possible, organise phone discussions with the carer/parent about how they could prepare their child for the appointment. Talking to children before their appointment about what to expect, and using the Your Dental Health dual read guide and videos are ideal tools (<a href="http://inclusiondesignlab.org.au/dental">inclusiondesignlab.org.au/dental</a>).</li> <li>iii. Does the accompanying parent or carer have access to the child's disability support plans (eg. behaviour plan, consistent approaches documents, Oral Care Plan)? Can you ask them to bring these documents to the appointment? Will they be supporting the child after the appointment?</li> <li>iv. Extra time may be needed to allow for a thorough assessment of the current Oral Care Plan – including diet, social, and medical history – and provide space to determine the barriers to good oral health care experienced by the child.</li> <li>v. Consider recommending appointments at quieter times for ease with transport and to help with behaviour and anxiety that may be experienced by the child.</li> <li>vi. Dental practitioners need to assess the child's ability to tolerate lengthy procedures. If the child is not in pain and does not need an emergency procedure, a series of preventative appointments can familiarise the child with the dental environment and the dental practitioner's approach ( i.e. build trust first). This may enhance the child's capacity to tolerate a lengthy procedure in the dental chair.</li> <li>vii. Good planning, familiarisation, and regular preventative appointments can help minimise the reliance on chemical restraints (sedation and general anaesthesia).</li> <li>viii. Preventive appointments and good oral home care can prevent diseases from manifesting themselves, and identify and address risk factors early.</li> </ul>
D	Are transport and scheduling arrangements required to get the child to the dental clinic? Is the clinic accessible to the child, including the main entrance, width of doorways, stairs, toilet facilities and the dental chair? Simply getting to the appointment can be a challenging experience for some children. Is accessible parking required and available? Accessibility is a journey for every organisation, business and workplace. Examining accessibility legislation and developing an accessibility plan is a great way to get started.

2 In the clinic: Interaction and roles of family members, carers and support professionals	
A	Where the accompanying person is not a primary caregiver or parent, what is the relationship of the accompanying person to the child? Does the person support or live with the patient regularly? Has the dental clinic requested that a regular staff person or family member attend the appointment? How well do they know each other? Can they provide consent for additional dental care if required?
B	If unsure of the frequency with which the accompanying parent or carer provides home oral care support to the child, it is appropriate for the oral health practitioner to ask for clarification.
C	Refer to the child's disability support plans (e.g. behaviour plan, consistent approaches documents, Home Oral Care Plan) when discussing possible side effects or pain, and when developing at home recommendations. Will the accompanying person be supporting the child after the appointment?

3 Communication, behaviour and consent	
A	<p>Instead of viewing consent as a one-off verbal affirmation, consent should be viewed as a process that begins in planning before the appointment and is confirmed:</p> <ul style="list-style-type: none"> <li>i. during the introductory conversations between dental practitioner, child and carer/parent(s), subject to the child's communication style</li> <li>ii. throughout the consultation, and</li> <li>iii. at the end of the consultation when planning future appointments.</li> </ul> <p>Consider sending forms to the child's home so that the carer/parent(s) responsible can have a conversation about consent, the appointment, and details about the treatment with the child before the appointment.</p>
B	Communicate using the style that the child or their parent/carer has identified as their preferred style. For many this will be simple, plain language. Communicate directly with the child and provide opportunity for accompanying supporters to be involved in the discussion and for the child to ask questions.
C	Spend a few minutes conversing in their communication style (and practising using communication equipment if relevant) before beginning clinical assessment/treatment. Invite feedback and guidance from the child and their carer/parent.
D	Consider altering the clinic/surgery environment e.g. dim lighting, non-white gowns and masks, music on/off, reducing loud sounds where possible.
E	If the procedure is lengthy, consider taking breaks. Involve the child and carer/parent in making decisions about what can be done to keep the child comfortable during the appointment.
F	Using a portable device or tablet, show videos or use pictures to explain any procedures that may cause concern to the child, including information about the X-ray machine, fillings, and complex procedures. The Your Dental Health video series and dual-read guide are ideal tools ( <a href="http://inclusiondesignlab.org.au/dental">inclusiondesignlab.org.au/dental</a> ).
G	The first appointment with the child will necessitate a further conversation related to future treatment options, including costs. It is important that parents or carers are informed about public and private options, and any additional significant costs that these options may incur.



4 Management of care at home	
<b>A</b>	It is vital that the child's Home Oral Care Plan makes its way to the child's home and onto a support plan. This might be a Person Centred Plan, a Support Plan or a Personal Schedule. Ensure that the instructions can be communicated clearly to carers, parents, and other support people. This may involve a slightly different process for each child or young person as each plan is different. Are there any other considerations that should be included in the Home Oral Care Plan.  <i>This step may be the difference between consistent and inconsistent oral health care for the child.</i>
<b>B</b>	The dental practitioner should discuss the Home Oral Care Plan with the carer/parent(s) including plan updates and manageability.
<b>C</b>	Ensure further appointments are booked. This may involve more frequent appointments or booking multiple appointments in advance.
<b>D</b>	Children with intellectual disability may be able to obtain funds through their NDIS plan to allow oral health professionals to come to their home, however this is on a case-by-case basis and is dependent on a range of factors such as level of support, diagnoses and outcomes. Encourage supporters to discuss oral health in detail with the child's NDIA planner.
<b>E</b>	When required, contact the child's allied health or other professionals.

### oral health and the NDIS

While oral health care cannot currently be funded by NDIS plans, there are ways that oral health professionals and NDIS plans can work together to improve the lives of children and young people with disability.

#### How can an NDIS plan help oral health?

A child or young persons' NDIS plan could fund a range of services to support the oral health care delivery and home oral care plans. These include:

- ▶ Dental or oral health therapy. In some cases NDIS funds can be used for professionals to train family or carers in maintaining good oral care at home
- ▶ Speech Therapy
- ▶ Occupational Therapy
- ▶ Physiotherapy or Exercise Physiology
- ▶ Dietician and Diet Plans
- ▶ Allied Health Assistant
- ▶ Counselling or Psychology

Where a child or young person is engaged with one of these services, they could support oral health by creating visual guides, support teaching good oral health techniques, or preparing for a dental visit.

**TIP** Talking to a child's other health professionals can be helpful as they may have noticed something that the child, parent, or support person is unaware of.

#### How can oral health professionals help with NDIS planning?

NDIA planner's write and develop a child's NDIS plan after meeting with the family and reviewing their evidence.

An oral health professional can support a family with NDIS planning by writing referrals to supporting services, and recommendations to the NDIA. A referral or letter may include:

- ▶ Why the child's oral health condition/issue is related to their disability
- ▶ What other support services could help fix or prevent poor outcomes
- ▶ How good oral health connects to one or more goals in the child's NDIS plan. By linking to a goal on the child's NDIS plan, they are more likely to get funding for that support.

It is advised that you liaise with a child's allied health professionals, in particular a Speech Pathologist. They have substantial experience writing referrals and recommendations for NDIS participants.

**TIP** Ask about NDIS plans and planning when you talk to parents, carers, and supporters. They may not know how oral health and NDIS can work together.

## effective planning

The forms on the following pages have been developed to aid communication between (a) dental practitioners and general practitioners(GPs/doctors) and (b) dental practitioners and the primary supporters of patients with intellectual disability.

The form is titled "oral health assessment" and is intended to be completed by a dental practitioner. It includes sections for Patient Information (Name, Address, Date of Birth, Practitioner details), a table for Relevant medical and allied health contacts, sections for Formal disability diagnosis, Existing dental issues and previous concerns, Other existing conditions, Current medications, and Allergies. It also has a section for Dental Assessment and a checklist for dental practitioners.

### oral health assessment

The dental practitioner can use this form to outline dental issues, support needs, treatment, and follow up protocols for the patient.

This form can be directly communicated to general practitioners(GPs/doctors), specialists, and other allied health professionals, allowing for a shared understanding of the link between oral health and overall health in the patient's life.

The form is titled "home oral care plan" and is intended for parents, families, and carers. It includes sections for Patient Information (Name, Name of parent(s), carer(s) or support professional, Name of dentist), a section for Daily Oral Care Routine (Brush teeth, Toothpaste, Interdental brush or Floss, Flossing, Toothbrush, Other, Reminder to brush), and a section for Assistance and support for daily oral care routine.

### home oral care plan

Dental practitioners can use this form to outline the ideal home care for the patient.

This form is best completed with the input of the patient and any supporters who accompany them to the appointment.

The form provides clear, simple directions for supporters so that they can gather helpful information using observation between appointments.





## references

- AAPD. (2004). *Clinical Guideline on management of persons with special Health care needs*. *Pediatric Dentistry* 2004:77-80
- Anders PL, Davis EL. (2010). *Oral health of patients with intellectual disabilities: a systematic review*. *Special care in dentistry*, 30(3):110-117.
- Bascones-Martínez A, Arias-Herrera S, Criado-Cámara E, Bascones-Ilundáin J, Bascones-Ilundáin C. (2012). *Periodontal disease and diabetes*. *Adv Exp Med Biol*, 771:76- 87.
- Batshaw ML, Shapiro B, Farber MLZ. *Developmental Delay & Intellectual Disability*. In Batshaw ML, Pellegrino L, Roizen NJ (eds.) (2007). *Children With Disabilities (6th ed.)*. Baltimore, MD: Paul H. Brookes Publishing Co.
- Bell E, Kaidonis J, Townsend G. (2002). *Tooth wear in children with Down syndrome*. *Australian dental journal*, 47(1):30-35.
- Binkley C, Johnson K, Abadi M, Thompson K, Shambien S, Young L, & Zaksek B. (2014). *Improving the Oral Health of Residents with Intellectual and Developmental Disabilities: An Oral Health Strategy and Pilot Study*. National Institute of Health.
- Botti Rodrigues dos Santos MT, Masiero D, Novo NF, Simionato MRL. (2003). *Oral conditions in children with cerebral palsy*. *Journal of Dentistry for Children*, 70(1):40-46.
- Centre for Oral Health Strategy NSW (2013). *Oral Health 2020*. [health.nsw.gov.au/oralhealth/Publications/oral-health-2020.pdf](http://health.nsw.gov.au/oralhealth/Publications/oral-health-2020.pdf)
- Davidson MA. (2008). *Primary care for children and adolescents with Down syndrome*. *Pediatric Clinics of North America*, 55(5):1099-1111.
- Deps TD, Angelo GL, Martins CC, Paiva SM, Pordeus IA, Borges-Oliveira AC (2015). *Association between dental caries and Down Syndrome: a systematic review and meta-analysis*. *PLoS one*, 10(6):e0127484.
- Desai SS. (1997). *Down Syndrome: A review of the literature*. *Oral Surg Oral Med Oral Path Oral Radiol Endod*, 84:279-285
- Dougherty NJ. (2009). *A review of cerebral palsy for the oral health professional*. *Dental Clinics of North America*, 53(2):329-338.
- Douglass AB, Gonsalves W, Maier R, Silk H, Stevens N, Tysinger J, Wrightson AS (2007). *Smiles for Life: A National Oral Health Curriculum for Family Medicine*. A model for curriculum development by STFM groups, *Family Medicine*, 39(2): 88-90.
- FDI World Dental Federation (2017). *FDI/IADH policy statement on Oral health and dental care of people with disabilities*: Adopted by the FDI General Assembly, September 2016, Poznan, Poland. *International Dental Journal*, 67(1): 16-17.
- Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L (2014). *The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study*, *The Lancet*, 383(9920): 889-895.
- Heslop P & Glover G (2015). *Mortality of people with intellectual disabilities in England: A comparison of data from existing sources*, *Journal of Applied Research in Intellectual Disabilities*, 28(5): 414-422.
- Hosking FJ, Carey IM, Shah SM, Harris T, DeWilde S, Beighton C, Cook DG (2016). *Mortality Among Adults With Intellectual Disability in England: Comparisons With the General Population*, *American journal of public health*, 106(8): 1483-90.
- Hutchins K, Carras G, Erwin J, et al (2009). *Ventilator-associated pneumonia and oral care: A successful quality improvement project*, *American Journal of Infection Control*, 37:590-7.
- Li X, Luan Q, Wang X, Sha Y, He L, Cao C, Jin L. (2008). *Nifedipine Intake Increases the Risk for Periodontal Destruction in Subjects with Type 2 Diabetes Mellitus*, *Journal of Periodontology*, 79(11): 2054-9.
- Loo CY, Graham RM, Hughes CV. (2008). *The caries experience and behavior of dental patients with autism spectrum disorder*. *The Journal of the American Dental Association*, 139(11):1518-1524.
- Mac Giolla Phdraig C, Nunn J, Dougall A, O'Neill E, McLoughlin J, Guerin S (2014). *What Should Dental Services for People with Disabilities Be Like? Results of an Irish Delphi Panel Survey*, *PLoS ONE* 9(11): e113393.
- National Institute of Dental and Craniofacial Research (NIDCR) (2009). *Practical Oral Care for People with Developmental Disabilities*, Bethesda MD, USA.
- Sievers K, Silk H, Quinonez R B and Clark M, (2010) (2014 version). *The Relationship of Oral to Systemic Health, Smiles for Life: A National Oral Health Curriculum*, STFM Group.
- Trollor J, Srasuebkul P, Xu H, et al (2017). *Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data*, *BMJ Open*, 7(2): e013489.
- Watanabe K. (2011). *Periodontitis in Diabetics: Is Collaboration Between Physicians and Dentists Needed?*, *Dis Mon*, 57(4): 206-213.
- Weddell JA, Sanders BJ, Jones JE (2004). *Dental problems of children with disabilities*. In McDonald RE, Avery DR, Dean JA. *Dentistry for the Child and Adolescent* (8th ed.). St. Louis, MO: Mosby, 524-556.

**Dr Jacquelyn Fechny**  
Paediatric Dentist, Australasian Academy of Paediatric Dentistry

**Dr Kareen Mekertichian**  
President, Australasian Academy of Paediatric Dentistry

**Nathan Despott**  
Inclusion Melbourne, Victoria

**Jenna Hepburn**  
Inclusion Melbourne, Victoria

**Dr Richard Zylan**  
Dentist, Dynamic Dentistry, Victoria

**Dr Jane Tracy**  
Centre for Developmental Disability Health, Monash Health, Victoria

**Dr Warren Shnider**  
Special Needs Dentist, Dental Health Services Victoria

With support from Dr Kerrie Punshon (Dental Health Services Victoria), Dr Archana Pradhan (University of Queensland), Carina Martin and Deb Miller (Carrington Health), Alexandra Lewis Gargett, Dr Ramini Shankumar (Monash Health), Dr Joanne Watson (Deakin University), Crystal McPhee (Deakin University), and Professor Hanny Calache (Deakin University).

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[asscid.org.au](http://asscid.org.au)







67 Sutherland Road Armadale VIC 3143

PO Box 8093 Armadale VIC 3143

T. 03 9509 4266

E. [projects@inclusiondesignlab.org.au](mailto:projects@inclusiondesignlab.org.au) W. [inclusiondesignlab.org.au](http://inclusiondesignlab.org.au)

 Inclusion Melbourne Inc.  InclusionMelb



Australasian Academy  
of Paediatric Dentistry

Website: [aapd.org.au](http://aapd.org.au)

Email: [president@aapd.org.au](mailto:president@aapd.org.au)