ACD

Snapshot: Experiences of dental care for children with disability and their families

October 2026

Background

ACD is the Victorian advocacy service for children with disability and their families. We are a not-for-profit organisation led by, and for, families of children with disability.

Our vision is an inclusive community where children with disability and their families thrive.

In August 2026, ACD held two Have Your Say online consultations with families about their experiences of dental services. The consultations aimed to understand what worked well, what was difficult, and what would make dental care more accessible and easier for children with disability.

For more information contact

Karen Dimmock CEO

karend@acd.org.au

0448 912 786

ACD acknowledges the Traditional Owners of this land. We recognise their continuing connection to land, waters and community. We pay respects to Elders past and present.

Executive summary

In August 2026, ACD held two Have Your Say online consultations with families of children with disability about their experiences of dental care. Families told us what has worked well, what has been difficult, and what would make dental care more accessible for their child.

Cost was one of the biggest barriers to dental care, with 71% of participants rating affording dental care as hard or very hard. Children with disability can need specialist paediatric care, treatment under sedation or general anaesthetic, and several visits to get comfortable before treatment can begin, all of which add to the cost. Some families were charged for appointments where little or no treatment took place.

Finding the right dentist was just as hard, with 71% of participants rating finding a dentist who could meet their child's needs as hard or very hard. With little clear information about dentists' experience working with children with disability, parents described searching practice websites, calling clinics and relying on other families and online parent groups to find someone suitable. This was even harder for families outside metropolitan Melbourne, where limited local options and workforce turnover meant some travelled long distances for care.

Many children needed specialist paediatric or hospital dental care, particularly for treatment under sedation or general anaesthetic. Some families tried several dentists before being referred to the specialist care their child needed. Once referred, getting into these services often meant more assessments, paperwork and waits of a year or more, and for some children, oral health got worse while they waited.

Once families found a dentist, the dentist's approach made a big difference to how well their child coped with dental care. Families valued dentists who were patient, explained things in a way children could understand, and built trust gradually rather than expecting children to go straight into an examination. Seeing the same dentist helped children know what to expect, while a change of dentist could set progress back. Reception and support staff who understood disability and did not judge also shaped families' experience.

The sensory demands of dental visits, from lights and noise to the vibration of the drill, and the lead-up to appointments could be emotionally exhausting for both children and families. Calm waiting areas, fish tanks and televisions on the ceiling, social stories, and letting children sit on a parent's lap or take breaks all helped. School-based programs such as Smile Squad were valued for providing care in a familiar setting alongside peers.

Most families received some helpful advice about caring for their child's teeth at home, but much of it was general rather than tailored to their child's needs. Many turned to occupational therapists and other families for practical ideas about toothbrushes, toothpaste and brushing.

Families asked for lower-cost familiarisation visits, flexibility when treatment cannot go ahead, and more affordable access to specialist care and treatment under general anaesthetic. They want clearer information about dentists' experience and training in supporting children with disability, and about clinic accessibility and available supports before visiting for the first time. They also called for shorter waits and clearer referral pathways for specialist care.

At the dentist, families want longer and more flexible appointments, the same dentist wherever possible, and disability awareness across the whole dental team. They also want practical oral health advice that fits their child's needs, and closer collaboration between dentists, occupational therapists and other allied health professionals.

Accessing dental care

Families shared their experiences of finding and accessing dental care for their child, including the barriers they faced and what helped them find services that could meet their child's needs.

Affording dental care

Cost was one of the biggest barriers families identified when accessing dental care for their child, with 71% of consultation participants rating affording dental care as hard or very hard. While the general cost of dental care was challenging for many families, participants highlighted that disability-related needs often increased costs.

"It is absolutely more difficult and more expensive [for children with disability to access dental care] … Many disabled people are at higher risk of grinding, clenching, teeth fractures, oral issues due to needing oral stimulation … It's quite complex and endless and higher risk than [the] general public."

Children with disability can require additional supports and services to access dental care. Additional costs raised by families included specialist paediatric dental services, treatment under sedation or general anaesthetic, and ongoing management of complex oral health needs.

"Cost is huge. I don't know how anyone does it without private healthcare. [We go] every 6 months … it has to be done under general anaesthetic, and, you know, that's thousands. … I worry about that. For her whole life … that it's going to be thousands every time she needs care."

Helping a child become comfortable with the dental environment could require multiple appointments before treatment could begin. While these visits helped children build familiarity and confidence, some families reported being charged for appointments where little or no treatment was completed, increasing the cost of care.

"They charge the same amount even if they do nothing or you don't even make it to the chair."

Families suggested changes that would help reduce the cost of dental care, including lower-cost familiarisation appointments and greater flexibility where treatment could not proceed. More affordable access to specialist dental services and treatment under general anaesthetic was also seen as important.

Finding the right dentist

Many families struggled to find a dentist with the knowledge, skills and flexibility to support their child, with 71% of consultation participants rating finding a dentist who could meet their child's needs as hard or very hard.

A lack of clear information about dentists' experience working with children with disability meant many families had to do their own research to identify suitable clinics. Two-thirds of participants rated finding reliable information about suitable dentists as hard or very hard. Parents described searching practice websites for references to disability and spending a lot of time contacting clinics to work out whether a provider would be a good fit for their child. Many turned to recommendations from other families, community networks and online parent groups.

"There's all that admin time as a parent, sort of searching and calling and trying to find someone suitable."

This was even harder for families living outside metropolitan Melbourne. Limited local options and workforce turnover meant some families travelled long distances to access care.

"I was not able to find someone suitably skilled locally. This means additional time off work for me and school for my son. It's a long round trip."

For some families, physical accessibility limited which dental services they could use. Families of children who use wheelchairs described treatment rooms that were too small for mobility equipment or support transfers, as well as inaccessible entrances and a lack of accessible bathrooms.

"A lot of dental surgeries, the rooms are really small … they aren't necessarily physically accessible."

Families wanted clearer information about dentists' experience and training in supporting children with disability, as well as clinic accessibility and available supports, particularly before visiting a clinic for the first time.

Specialist paediatric dental services

For many children with disability, specialist paediatric and hospital-based dental services were needed to access treatment, particularly for complex needs or treatment under sedation or general anaesthetic not available through general dental clinics.

Getting into specialist care could be complex and time consuming. Families faced repeated referrals, assessments, paperwork and long waits before treatment could begin. Some described trying multiple providers before reaching the specialist support their child needed.

"We had to wait on a waitlist over a year with the dental hospital to be seen initially."

"You fill in all these forms, you wait so long for appointments, you go in, you get assessed, and then even then, you've still got to wait."

For some families, long waits meant their child's oral health worsening and treatment becoming more complex.

"He went from having one black spot to needing silver implants."

Children with complex disability and health needs could face additional barriers accessing specialist dental treatment. For one family, a private paediatric hospital declined treatment because of the complexity of their child's needs.

"The private hospital said that my child is too complex. They refused to take my child for surgery. The Children's has a 12-month internal waiting list, so we basically had to go back onto the waitlist."

Families wanted shorter waiting times for specialist assessment and treatment, earlier information about specialist care options, and clearer referral pathways between community, specialist paediatric and hospital dental services, and better access to treatment under general anaesthetic.

Experiences at the dentist

Building trust and relationships

Building trust and positive relationships with dentists and dental staff was central to successful dental care for many children with disability. Families valued dentists who took the time to build familiarity and confidence, recognising that positive dental experiences often developed gradually. Rather than expecting children to go straight into an examination or treatment, these dentists focused on small steps forward, such as helping children get comfortable with the room, equipment and staff first.

"He said, 'It's alright, you don't have to show me your mouth today, it's okay.' He was very calming, very non-confrontational, and very gentle."

Families noticed significant differences between dentists, with some approaches making it easier for children to undergo dental treatment than others. Dentists who were patient and willing to adapt their approach were better able to work with children. In contrast, rushed appointments, pressure to complete treatment, or a lack of understanding of disability could make the experience more challenging and affect a child's willingness to attend future appointments.

"It was just like magic. My son went in, and he opened his mouth for her for as many seconds as she wanted, as many times as she needed … My son would not let the dentist go anywhere near his head, let alone open his mouth. This woman was extraordinary in the way she approached him."

Seeing the same dentist and support staff across appointments helped children understand what to expect and feel more comfortable over time. Some families experienced setbacks when a trusted clinician was unavailable or appointments involved unfamiliar staff.

"There is a female dentist there who my son will tolerate going in his mouth. [She] wasn't there on a particular day, so [another dentist] took [our appointment], and then he just barged in and had no idea what he was doing. It's now taken us another three years to getting back to where [my child] was before."

Understanding disability and individual needs

Families wanted dentists to understand disability and recognise how a child's individual needs could shape their experience of dental care and the way treatment was delivered.

"Things that are really important, [like understanding] that lignocaine doesn't work the same way [for our child], nitrous oxide doesn't work the same way. And then when you add in connective tissue disorder, they have to be really aware of how they're treating the gums and stuff like that … education and awareness of complexity is incredibly hard to find in a dentist."

Families valued dentists who took the time to answer questions and explain procedures in a way children could understand. They also highlighted the importance of children not being left feeling like they had failed when treatment was unable to go ahead.

"It was really important [for our son] to really understand what was coming next … having someone who was really patient and able to explain it in plain English that he was able to understand, I think that made a huge difference for him."

Families also highlighted the role of reception staff, dental assistants and other team members in shaping their experience. They valued staff who understood disability, communicated respectfully with children and families, and responded in a supportive and non-judgemental way.

"We've got a really great receptionist that cares … she's obviously been taught how to work with these kids and not judge, because you feel judged constantly."

Sensory environment and emotional impact

For many children with disability, the sensory demands of dental care could be overwhelming. Lights, noise, smells, unfamiliar equipment and the physical sensations of dental treatment could all contribute to distress.

"The sensory aspects of drilling, and being told, 'It doesn't hurt', but the sensory aspect of the vibrations is very difficult."

For many families, the stress of dental visits began before the appointment itself. Preparing their child for the visit, managing anticipation and supporting them in the lead could be emotionally exhausting for both children and families.

"It's one of the most challenging experiences for those with sensory needs, so it requires so much planning ahead and emotional energy to complete a visit."

Families also shared examples of environments and supports that made appointments easier. Fish tanks, toys, televisions on the ceiling and sensory-friendly waiting areas helped children feel more comfortable before and during appointments.

Helping children understand what to expect before an appointment was seen as an important way to reduce distress. Families identified a range of strategies that had helped, or that they felt would help, including social stories, photos, videos, pre-appointment visits and getting used to dental equipment.

"Having the dental mirror at home helped get my child ready."

Flexible approaches to dental visits

Many families felt a more flexible approach to dental care was needed. Standard appointments did not always work well for children who needed additional time or support. Practical adjustments such as letting children sit on a parent's lap or take breaks, and adjusting expectations about what could be achieved in a single visit helped make appointments more manageable.

"A successful visit can be no dental work completed but they opened their mouth the first time."

"Allocate more time [per] visit so they are not rushing patients with special needs."

School-based programs such as Smile Squad were highlighted as reducing several practical barriers to dental care. Families valued children receiving care in a familiar environment alongside their peers. They also spoke positively about the communication and follow-up provided through the program. One family noted that receiving care through school gave their family a break from the emotional stress of dental and medical appointments.

"The Smile Squad made a big difference, because the other children were doing it, and it was all at the school. We had phone calls, we had text messages, to work out all the

logistics, and it was just the personal care and information we received … I hadn't experienced anything like it before. They booked us in for longer, so it didn't feel rushed. He was able to ask questions, he was able to put his hand up for a break."

Support for oral health at home

Families discussed the advice and support they had received to help care for their child's teeth at home, including what they found useful and where gaps remained. Most families found at least some of the information provided by dentists helpful. However, participants described gaps in advice tailored to the needs of children with disability, and some found standard advice difficult to apply.

"We got the basic information, but not really anything disability specific."

Several families turned to occupational therapists and other allied health professionals, as well as other families and online networks. In some cases, these sources were viewed as more helpful than dentists in managing day-to-day brushing and oral hygiene at home.

"Our OT was more helpful than the dentist with suggesting toothbrush options."

"Most amazing advice has come through other families."

Families particularly valued advice that was practical and specific to their child's needs, including alternatives when standard approaches were not working. They also appreciated guidance on fluoride use, toothpaste and toothbrush options, flossing, and preventing tooth decay, given how difficult future treatment could be for their child.

"My daughter doesn't like using toothpaste. Instead of the dentist just constantly saying, 'Well, she needs to use toothpaste,' she actually found alternatives for us. She didn't make it a big deal, like, 'Your kid's not brushing their teeth twice a day, you're doing something wrong.' She was able to say, 'Okay, this is an alternative to what you can do if they're not going to brush their teeth' … just having a dentist offer alternatives, and not just say, 'This is the blanket rule.'"

Families also saw value in closer collaboration between dentists, occupational therapists and other allied health professionals, particularly where a child needed additional support with brushing or other aspects of oral care at home.

Families who participated

Twenty-four families took part in two online consultations. Their children ranged in age from five to 21, with an average age of 10. The most reported primary disability was autism, followed by ADHD and intellectual disability. Eight participants identified as culturally and linguistically diverse.

Seventeen families were from metropolitan Melbourne, and seven from regional areas.

Appendix

During the consultations, families rated how easy or hard it was to get dental care for their child, and how helpful their dentist's oral health advice had been. The tables show how many families gave each rating.

Table 1: How easy or hard families found getting dental care for their child (1 = very easy, 5 = very hard)

Aspect of dental care	1 (very easy)	2	3	4	5 (very hard)	Average rating
Finding reliable information about suitable dentists	0	3	5	9	7	3.83
Finding a dentist who can meet your child's needs	1	2	4	7	10	3.96
Waiting times for appointments	2	4	5	7	6	3.46
Affording dental care	2	1	4	5	12	4.00
Finding a dentist close to home	1	6	7	5	5	3.29
Accessing specialist paediatric dental services (if you've needed it)*	2	4	2	7	5	3.45

Twenty-four families answered each question, except accessing specialist paediatric dental services, which was answered only by the 20 families who had needed it.

Table 2: How helpful was the information your dentist provided about looking after your child's teeth at home?

Choices	Votes
Not at all helpful	0
A little helpful	5
Somewhat helpful	7
Very helpful	9
Extremely helpful	2
I didn't receive any advice	0

Twenty-three families answered this question.