

Assessing dental caries experiences and dental service delivery for children with disabilities in Auckland, New Zealand: a mixed-method study

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ABSTRACT

Introduction. Despite free dental care for children under 18 in New Zealand, children with disabilities face significant barriers to accessing these services, leading to disproportionately poorer oral health outcomes. A detailed understanding of the oral health status and service delivery for children with disabilities is essential to identify existing gaps and areas for improvement. **Aim.** The study aims to examine the oral health status of children with disabilities in Auckland, New Zealand and explore the perspectives of clinicians and service managers working in the community dental service regarding oral health care for these children. **Methods.** An explanatory sequential mixed-method design was utilised. The initial quantitative phase involved retrospective analysis of dental records of children with disabilities who received care through the community dental service. This was followed by the qualitative phase, which consisted of semi-structured interviews with clinicians and service managers. **Results.** The study identified high caries rates and significant unmet dental care needs among children with disabilities. Clinicians and service managers recognised individual-level challenges, such as insufficient confidence and training. Additionally, broader systemic issues, including inadequate service design and barriers in service delivery, were also highlighted, contributing significantly to oral health disparities. **Discussion.** This study highlights the urgent need for tailored dental services for children with disabilities in Auckland. It emphasises the importance of integrated care approaches and enhanced training for dental professionals to improve accessibility and outcomes in paediatric dental health care.

Keywords: children, community dentistry, dental care, dental caries, dental diseases, disability, paediatric dentistry, public health dentistry.

Introduction

The term ‘disability’ is ‘an umbrella concept encompassing impairments, activity limitations, and participation restrictions’,¹ which includes physical, sensory, cognitive, or emotional impairments. Children with disabilities, often underserved in health care and education, face unique challenges in accessing dental care.² Their specific health conditions, potential medication side effects such as xerostomia, and behavioural issues affecting diet can increase their risk for dental diseases, leading to poorer oral health outcomes compared to peers without disabilities.^{2–5} Due to their disabilities, these children often need additional support with oral hygiene practices, such as brushing their teeth and maintaining a healthy diet to prevent dental issues. Developmental and neurological impairments may also modify their response to sensory stimuli, influencing their comfort with oral hygiene routines.⁶ Consequently, children with disabilities rely heavily on caregivers for daily life skills, including oral hygiene, which may be overlooked if caregivers focus primarily on general health. In addition to the challenges faced at home, this population group often presents lower utilisations of dental care services.³

WHAT GAP THIS FILLS

What is already known: Children with disabilities in New Zealand, despite having access to free dental care, experience barriers that prevent them from receiving adequate oral health services, leading to poorer outcomes compared to their peers without disabilities.

What this study adds: This research provides evidence of high caries rates and substantial unmet dental needs among children with disabilities in Auckland and identifies specific systemic and individual-level challenges in service delivery. It advocates for an integrated care approach and enhanced professional training to address these disparities effectively.

Research on caries experiences among children with disabilities shows mixed findings. A meta-analysis of 26 studies found that children with intellectual disabilities had higher plaque levels and worse gingival status but fewer caries in permanent teeth.⁷ Another meta-analysis reported no significant caries differences between children with and without learning disabilities, except for those with Down Syndrome, who had fewer caries in permanent teeth.⁸ Contrarily, in 2023, 10.4% of Aotearoa New Zealand (NZ) children had their teeth removed due to dental caries, with the prevalence rising to 19% among children with disabilities.⁹ Challenges in getting access to oral healthcare services and having comprehensive dental examinations were suggested as potential factors masking the true caries experiences of children with disabilities.⁷ Additionally, the varying definitions of 'disabilities' across studies complicate the comparison and generalisation of findings.

In NZ, state-funded dental care is provided to individuals under 18, primarily by dental therapists¹⁰ and oral health therapists¹¹ who are trained in a wide range of dental treatments and procedures necessary for children and adolescents. These professionals, along with community and hospital dentists and dental specialists, work under Health New Zealand Community Oral Health Services (COHSs) to deliver care in various community settings, such as community-based, school-based, mobile, and hospital clinics. The Auckland Regional Dental Service (ARDS) is a regional COHS provider in Auckland, where children, including those with disabilities, are enrolled from birth and receive tailored dental care.¹² Many children with disabilities undergo treatments under general anaesthesia (GA) at hospital clinics, which often have long waiting lists, highlighting the need for more accessible and efficient service delivery. The necessity of GA for certain children due to their specific medical and behavioural needs highlights the importance of optimising these services for timely and effective care.

One cohort study in NZ indicated that children with neurodevelopmental disabilities face a higher hazard ratio of dental hospitalisation admissions of 3.40 and a higher caries

experience of 17.6% compared to their peers (14.3%).¹³ Additionally, a report on oral health research priorities for Māori (NZ Indigenous population) highlighted the need to further explore the caries risk of children with disabilities and their caregivers.¹⁴ Despite the availability of dental care through COHS and the hospital system, there is a notable lack of literature on the service delivery models, oral health outcomes, and experiences of children with disabilities, their caregivers, and clinicians.

Given the conflicting international findings on the dental caries rates of children with varying disabling conditions and the limitations of research conducted in NZ, a significant gap in the literature requires further exploration. This study aims to investigate the dental characteristics profile of children with disabilities in Auckland, addressing the need for more targeted research to better understand this demographic's unique oral health needs. The objectives of this study are (1) to examine the oral health status of children with disabilities in Auckland, and (2) to explore the perspectives of clinicians and service managers in ARDS regarding oral health care for these children.

Methods

The study adopted an explanatory sequential mixed-method design and conducted quantitative research followed by qualitative research.^{15,16} Quantitative research findings informed questions for qualitative research. This approach allowed the researchers to identify gaps in knowledge from quantitative research and then complement it with qualitative findings. Ethical approval was obtained from the Auckland Health Research Ethics Committee before the commencement of the study (AH21650) for both quantitative and qualitative research. Further locality approval was obtained from the Waitemata District Health Board Research and Knowledge Centre to access the ARDS patient records for the retrospective analysis study.

Phase 1: quantitative arm

A retrospective audit design was used to assess the oral health status of children with disabilities aged between 5 and 13 in Auckland, using records from January 2021. The age range was chosen because preschool children are less frequently examined, and those over 14 are typically referred from ARDS to general dental practices. Due to the extensive volume of patient records, a practical approach was taken by utilising a list from specialist schools and satellite units to identify relevant dental records in the ARDS electronic database. Key demographic data included gender, age, medical conditions, school decile¹⁷ (indicative of socioeconomic status, with one being the lowest), and primary ethnicity. The clinical impact of dental caries was measured using DMFT/dmft scores, though these were not differentiated between

permanent (DMFT) and primary (dmft) dentition (DMFT, dmft: decayed, missing due to caries, and filled teeth). Due to variability in recording, specific medical conditions were not detailed. For the purpose of this study, children with chronic medical conditions or developmental needs who were enrolled in specialist educational settings were included under the designation of children with disabilities. While this grouping may not fully align with all clinical definitions of disability, it reflects how children are identified and supported within NZ's education and dental service systems. It is also consistent with the definition outlined in the Convention on the Rights of Persons with Disabilities,¹⁸ which recognises persons with disabilities as 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'. Caries risk was categorised as low, medium, or high, and data on access to dental facilities and radiography were also collected. Data analysis was conducted using R version 4.0.3 and R-Studio, using descriptive statistics and multiple generalised linear model analyses to explore associations between variables.

Phase 2: qualitative arm

For the qualitative component, in-depth semi-structured online interviews were conducted with clinicians and service managers employed by ARDS in February and March 2022. Purposive sampling¹⁹ targeted frontline clinical staff who regularly interact with children with disabilities and ARDS senior management overseeing service operations. Eligible staff received a participant information sheet and consent form; upon returning consent via email, they were scheduled for either a physical or virtual 1-h interview based on their preference. All interviews were conducted by one interviewer, a

registered dental therapist, who began each session by sharing a summary of the quantitative findings to guide discussion on specific issues requiring insights from both clinicians and managers. The interviewer also disclosed any potential conflicts of interest. Interviews were audio-recorded, transcribed in Microsoft Word with all identifying information removed, and analysed using a general inductive approach²⁰ to condense data into summarised findings that are connected directly with the research objectives. Transcripts were thoroughly reviewed to ensure saturation before coding. Codes were then grouped into categories and analysed to explore relationships and answer the research question.

Results

Quantitative findings

Of 291,651 children enrolled in ARDS in January 2021, 990 children met the inclusion criteria and were found to be enrolled in high-needs specialist schools in Auckland. Table 1 shows demographic characteristics and clinical records of the study population. The mean age of the sample was 9.25 years (s.d. \pm 2.45) and ranged from 5 to 14 years. More than half (69.0%) were identified as male (Table 1). For clinical records, the majority (69.6%) were categorised as high caries risk patients by the clinicians, and nearly all patients (91.1%) had medical conditions recorded in their patient files. Additionally, radiographic assessments were not common (29.8%) for this demographic.

There were 990 children with DMFT scores with a mean of 1.89 (95% CI 1.76–2.02). There was no statistically significant difference between the two genders (Table 1). Patients aged 5–7 years had significantly higher overall DMFT scores of 2.14 than the overall DMFT scores of 1.89

Table 1. DMFT scores of children with disabilities enrolled in Auckland Regional Dental Services.

Variable	Number of children (%)	Mean DMFT score	95% confidence level, lower limit	95% confidence level, upper limit	P-value
Overall	990 (100.0)	1.89	1.76	2.02	–
Gender					
Male	683 (69.0)	1.88	1.78	1.99	1
Female	307 (31.0)	1.91	1.76	2.07	0.798
Ethnicity					
European	202 (20.4)	1.91	1.73	2.11	1
Māori	217 (21.9)	2.22	1.20	1.51	0.028*
Pasifika	262 (26.5)	1.91	1.78	2.12	0.806
Asian	217 (21.9)	1.35	1.20	1.51	0.000*
Other	92 (9.3)	2.18	1.90	2.51	0.124

DMFT, decayed, missing, and filled teeth.

*Statistical significance: $P < 0.05$.

($P < 0.01$). When data were categorised by ethnic groups, Māori children with disabilities had the highest score, while Asian children had the lowest score compared to other ethnic groups (Table 1).

Qualitative findings

Five online semi-structured interviews were conducted, and participant demographics included two dentists (one male and one female), two dental therapists (two females), and one oral health therapist (male). Three were in management roles, and two were frontline clinicians. Years of experience in the dental sector ranged from 7 to 30 years. Following analysis using a general inductive approach²⁰ of transcribed data, four main themes were identified: (1) service design and delivery issues, (2) perceived challenges and barriers for individual clinicians, and (3) recommendations for service delivery improvements.

Service design and delivery issues

The issues highlighted by the participants point towards systemic inefficiencies and design flaws in service delivery for children with disabilities. The existing structure and availability of services are fragmented and not designed collaboratively with frontline workers or end-users, leading to inefficiencies and inadequate care pathways, while long waitlists for dental appointments further complicate access:

The structure is the issue. How it is structured to get the services to [children with disabilities] is not designed for them. (Participant 4)

Many participants emphasised a lack of specialised tools and equipment for children with disabilities, such as wheelchair access and specialised chairs, leading clinicians to adapt to suboptimal conditions.

Furthermore, the interviews highlighted service inequities in dental care for children with disabilities. They are often not being prioritised or correctly identified within the system, leading to inadequate referral processes and the failure to track and manage their care properly:

The children get completely lost out of the ARDS system and the adolescent system all because we failed that child by not referring them appropriately to specific [practitioners] who would manage them. (Participant 1)

The lack of integration with other essential services, such as education and occupational therapy, creates coordination challenges and barriers to comprehensive care. There is a clear absence of specific policies and streamlined pathways for managing dental care for children with disabilities, leading to systemic issues such as inappropriate referrals and the potential for these children to be lost in the system:

There needs to be a lot of improvement in regard to children with disabilities. There is no definite pathway. There is no set pathway or good policy of who sees [children with disabilities]. (Participant 3)

Perceived challenges and barriers for individual clinicians

Participants emphasised the importance of having accurate and updated medical information for dental care for any patients with or without disabilities. However, some participants highlighted challenges in recording children's disabilities due to some caregivers' reluctance to disclose this information to clinicians:

A lot of parents don't use [medical history form] to disclose that their child is disabled, so we don't know. Some parents even refuse to disclose it when questioned. (Participant 1)

Some participants use alternative methods, such as reviewing national hospital records to identify undisclosed conditions to provide safe and necessary care to children. The inconsistency in recording medical histories was also a concern, as essential information could be missed or misplaced when not uniformly recorded in designated sections such as the medical notes. This was suggested as a potential explanation for missing medical information for some patients from the quantitative study.

Participants identified the lack of caregiver engagement, as many caregivers do not consider oral health a priority, leading to a low demand for dental services among these families. Difficulties in obtaining consent and outdated contact information further complicate the process, with schools often being the only point of contact. This disengagement necessitates greater family involvement to effectively access and utilise dental services, without which efforts to improve care remain stalled:

[Clinicians] need family involvement. If [families] do not make efforts to access the services, [clinicians] will be back where we started. (Participant 3)

Additionally, participants highlighted a significant gap in the dental team's training and confidence when managing dental care for children with disabilities. Although it was recognised that many instances of GA are not solely for dental purposes but are mixed-purpose and GA might be the only option to provide care to some children with disabilities, some participants noted an over-reliance on GA for treatments, which could often be managed without it due to a lack of specific training in oral health care for people with disabilities. This suggests a pressing need for tailored training to enhance clinicians' confidence and competence, allowing for more effective and less invasive dental care management for these children:

[Clinicians] have not had training in caring for children with disabilities. I suppose there are varying degrees of confidence among staff. (Participant 2)

Recommendation for service delivery improvements

Participants suggested several improvements for dental service delivery to children with disabilities, emphasising the need for workforce development and better prioritisation of these children. Upskilling of dental staff was crucial to enhancing confidence and competence in managing severe dental needs. Participants proposed more focused training on technical skills and cultural safety aspects to address diverse needs effectively:

I think the management of children with severe dental needs is a matter of upskilling. That way a clinician could better manage a child with severe dental needs. (Participant 5)

Moreover, enhancing relationships with parents, caregivers, and the broader disability communities was identified as vital to improving the oral health outcomes of these children. Building strong connections with schools, public health nurses, and other services is crucial for facilitating appointments and comprehensive care. Participants advocated for an integrated healthcare approach, suggesting a 'one-stop-shop' model where multiple health needs are addressed in one visit, easing the burden on families. They also stressed the importance of continuity of care beyond 18, suggesting that services should be free for adults with special needs to address ongoing inequities and ensure comprehensive, lifelong care.

Discussion

This study utilised a retrospective audit of dental records to assess the oral health status of children with disabilities in Auckland and gathered insights from clinicians and service managers about oral health care and organisational operations. The findings indicated statistically significant higher DMFT scores of 2.14 among children aged 5–6 years with disabilities. The average DMFT score for all 5-year-old children in the general population in 2021 was 1.95, indicating poorer oral health outcomes among children with disabilities.²¹ This disparity is significant, considering DMFT scores are typically elevated at age five due to their first comprehensive dental examination. The challenges of conducting thorough dental examinations on children with disabilities – due to behavioural, communication, or physical limitations – may lead to underestimations of their oral health conditions.²² Additionally, children with severe impairments often receive care in hospital settings rather than through community oral health services, and are not included in this data. Although direct comparisons with other countries may not be completely valid due to different dental care

frameworks, similar issues of poorer oral health outcomes in children with disabilities are recognised globally,^{23,24} such as in a German study which reported an average DMFT score of 2.1 in children with disabilities aged 6–11 years.²³

The Waitangi Tribunal Hauora Report²⁵ confirmed that the Crown has failed to meet its obligation of Te Tiriti o Waitangi (the founding document of NZ) to address Māori health inequities, including those in oral health. Notably, while 10.4% of all children in NZ underwent dental extractions due to caries, the rate was higher at 15.5% among Māori children.⁹ The current study found that Māori children with disabilities had a significantly higher DMFT score (2.22) compared to European children with disabilities (1.91), with the difference being statistically significant ($P < 0.05$). This documented inequity has resulted in Māori children suffering from amplified health and social burdens.²⁶ A Te Tiriti lens is essential for examining this inequity and implementing more specific and effective interventions to reduce disparities and improve outcomes for Māori.²⁷ The importance of implementing culturally safe interventions that support applying the principles of Kaupapa Māori²⁸ and maintaining the cultural connectedness between service users, their families, and service providers²⁹ cannot be overstated, as it is critical to achieving better and more equitable oral health outcomes.

The strength of this study lies in its integration of qualitative insights with quantitative data, exploring the challenges ARDS clinicians and service managers face in delivering effective care to children with disabilities. The findings indicate significant service access and delivery issues, exacerbated by limited resources and poorly designed service structures,^{30–32} aligning with issues identified in a systematic review,³³ such as physical inaccessibility and inadequate interdisciplinary collaboration. It is crucial to develop facilities that are universally accessible and environments that cater to diverse needs.³⁴ The current study also highlights challenges clinicians face, emphasising the need for specialised training. Participants considered that the lack of specialised training and low staff confidence among dental teams led to over-reliance on GA for manageable treatments. It is important to acknowledge, however, that many instances of GA are not solely for dental purposes but are mixed-purpose. Frequently, oral health teams utilise occasions when children with disabilities are already scheduled for GA for other medical treatments to address various health needs, including dental care, simultaneously. This approach signifies the complexity of care coordination in children with disabilities and highlights the necessity of multifaceted training that prepares dental professionals to make informed decisions regarding using GA in the context of overall patient care.

Some participants shared their experiences of having some caregivers who are reluctant to disclose disabilities or do not prioritise oral health, thus complicating the safe and effective treatment process for children with disabilities. Caregiver motivation is crucial in managing the oral health care of their children with disabilities, influencing everything from maintaining oral hygiene and utilising

dental services to implementing dietary changes and raising oral health awareness.^{33,35,36} Understanding the factors that influence caregivers' behaviours remains a complex challenge. Multiple variables, including cultural beliefs, socioeconomic status, past experiences with health care, and educational levels, can significantly impact how caregivers manage the oral health of children with disabilities.⁵ Oranga Waha: Oral health research priorities for Māori highlighted caregivers' perceptions that they did not know how to access dental care in NZ for children with disabilities.¹⁴ The report highlighted the necessity for education about the connection between oral health and disabilities and the ways to access essential care for individuals with disabilities.¹⁴ Thus, it is critical to explore these diverse influences to comprehend the particular needs of caregivers and families. Such understanding facilitates the practical tailoring of services to meet these requirements, ultimately leading to improved oral health outcomes for children with disabilities.^{37,38}

The current study was the first to map out the impact of oral health service delivery on the dental caries experiences of children with disabilities in Auckland and to explore the views of clinicians and service managers. While the findings are specific to Auckland, they are relevant to other regions since COHSs across NZ operate under similar service frameworks established by Health New Zealand. However, the study faced several limitations, such as incomplete medical histories, inconsistent clinical note-taking, and uncalibrated risk assessments for dental caries based on individual clinical judgments. Notably, the study found that 69% of the children with disabilities were male, but without additional data, further analysis was constrained. The inability to differentiate findings based on specific types of disabilities limited the depth of quantitative analysis and reduced the ability to identify associations between particular disability types, caries experience, and access to care. These factors indicate potential challenges in confidently interpreting the correlation between DMFT scores and disability status, particularly as the classification of disability relies on available clinical records rather than standardised diagnostic criteria. Furthermore, the inclusion criteria for children with disabilities were based on enrolment in specialist educational settings and recorded medical conditions, which may not fully capture the clinical diversity or reflect standard definitions of disability. These methodological constraints highlight the need for more rigorous controlled studies to assess the oral health of children with disabilities, particularly through comprehensive analyses of caries experience and access to care across different disability types. Additionally, the study only included perspectives from clinicians and service managers, omitting the crucial viewpoints of the children with disabilities and their caregivers. Future research should incorporate these perspectives to enhance service delivery and inform policy development throughout NZ. Lastly, the challenges of the COVID-19 pandemic during data collection further complicated access to necessary information,

delaying the analysis and the research dissemination processes.

Enhancing the accuracy of oral health statistics for children with disabilities and providing additional support for clinicians are crucial. The NZ Ministry of Health currently does not segregate data between children with and without disabilities, which prevents accurate analysis of oral health outcomes. Prioritising data segregation is essential to ensure these children's health needs are clearly represented and addressed. Furthermore, workforce development is critical; dedicated funding and resources must be allocated for training and support to develop necessary skills. Research indicates that limited experience, inadequate education, and minimal clinical exposure contribute to practitioners' reluctance to treat patients with disabilities.³⁹ Integrating specialised programmes into undergraduate and postgraduate dental curricula can equip the entire oral health workforce to serve this population better.^{39,40} Establishing a multidisciplinary specialised clinic for individuals with disabilities would centralise essential services, promote inter-professional collaboration, and significantly reduce health disparities by improving both oral health care and the management of other medical conditions through coordinated diagnostic and treatment practices.^{41,42} These measures are vital for overcoming the systemic challenges highlighted in the study and improving overall care.

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