

# Oral health in children and adolescents with special healthcare needs in South Africa: A narrative review

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## INTRODUCTION

Children and adolescents with special healthcare needs (CWSHCN) may experience disproportionately poorer general and oral health than healthy children.<sup>1-3</sup> They are more at risk of common conditions such as dental caries and gingivitis resulting from poor oral health.<sup>4</sup> They comprise of children and youth “with or at risk of chronic physical, developmental, behavioural or emotional conditions”,<sup>5</sup> including, inter alia, intellectual disability (ID), cerebral palsy (CP), learning disability (LD), autism spectrum disorder (ASD), hearing impairment (HI), Down Syndrome (DS), physical disabilities (PD), visual impairments (VI) and epilepsy (EP). Globally, the prevalence of disabilities is increasing, even in developing countries such as South Africa (SA), resulting in a greater burden on healthcare systems.<sup>6</sup>

The 2011 World Health Organisation (WHO) report estimated that 15% of the global population had a disability. There was a slightly higher prevalence of individuals with disabilities in developing countries than in developed countries.<sup>7</sup> Among children aged 0-14 years and those above 15 years, 5.1% or 93 million and 19.4% or 892 million had a moderate or severe disability, respectively. Due to the lack of current epidemiological data, there are no accurate figures of children with disabilities in SA. However, the 2011 census in SA found that about 609,671 children aged between 5-14 years had a disability.<sup>8</sup>

Individuals with developmental disabilities such as ASD are more likely to develop oral diseases compared to typically developing children.<sup>9</sup> Poor dietary choices and between meal consumption of sugars increase the risk for dental caries,<sup>10</sup> while inadequate oral hygiene additionally increases the susceptibility for gingivitis. Children with ID may lack the cognitive and/or manual dexterity to perform oral hygiene independently, while uncooperative behaviour

makes routine oral hygiene practices difficult for the parent/caregiver. Furthermore, medication such as phenytoin, an anticonvulsant drug used in children with epilepsy, may predispose to gingival hypertrophy<sup>11</sup> and impede proper plaque control. Caries risk also increases in the presence of developmental defects of enamel and enamel hypoplasia that may be present in young patients with CP.<sup>12</sup>

Poor oral health can negatively impact general health, especially in children with disabilities.<sup>13</sup> When left untreated, dental caries leads to chronic pain, infection, sleep disruption, premature tooth loss and poor weight gain as the child cannot feed properly, which may impact growth and development.<sup>14</sup> Dental infections resulting from poor oral health also pose a risk for bacteraemia and potential life-threatening septicaemia, especially in immunocompromised children.<sup>15</sup> Mostly, the oral health management of CWSHCN is performed under general anaesthetic. The time and cost associated with treatment under general anaesthesia puts additional strain on the healthcare system, especially in developing countries.<sup>16</sup> Furthermore, there is an associated economic burden on families related to the cost of treating oral diseases,<sup>17</sup> more so for CWSHCN with additional healthcare needs.

Despite the adverse consequences of poor oral health, globally CWSHCN are likely to encounter barriers to dental care services.<sup>18</sup> In addition, factors related to the severity of the child's disability and the family's socioeconomic level may limit access to non-preventative dental care.<sup>19</sup> In SA, the lower socioeconomic groups suffer from a greater burden of ill-health and disability and are less likely to use health services.<sup>20</sup>

Understanding the characteristics and status of oral health among CWSHCN helps to reveal their needs more specifically and address any barriers to dental care. In the area of oral health for individuals with disabilities, only a few studies have been conducted in SA, a country which has significant health inequalities.<sup>21</sup> Thus, the aim of this review was to describe the characteristics and status of oral health among CWSHCN in SA. The study forms part of a PhD programme for the principal investigator (NN).

## MATERIALS AND METHODS

### Search strategy

A literature review was conducted based on the PRISMA 2020 statement for systematic reviews.<sup>22</sup> An internet-based search was performed for the articles published between January 1 2002 and August 31 2023. This period was chosen as the last SA National Children's Oral Health survey (NCOHS) was conducted two decades ago (1999-2002).<sup>23</sup> Notably, CWSHCN were not included in the survey. The keywords used were: oral health, dental caries, children/adolescents and South Africa. The following electronic

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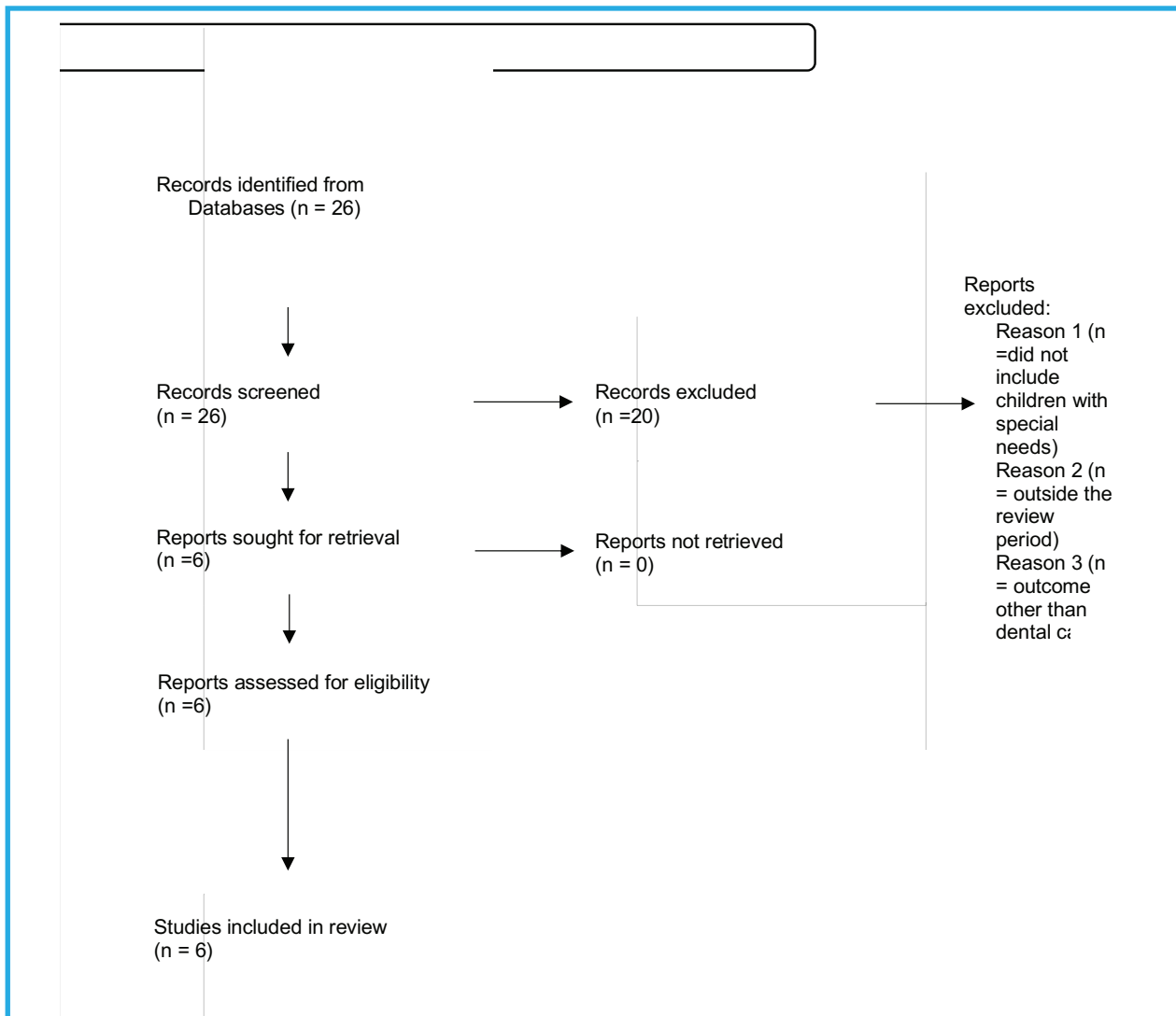


Figure 1. PRISMA 2020 statement flow diagram for selection of studies.

databases were searched for studies that met the eligibility criteria for this review: MEDLINE, PubMed, SCOPUS.

### Eligibility criteria

The eligibility of potential studies was determined by reading the title and abstracts of each article identified by the search engine. All articles that appeared to meet the inclusion criteria based on their abstracts were selected and collected. Full-text articles were obtained for manuscripts with missing abstracts or those in which insufficient relevant information was found in the published abstract. Reference lists of the included studies were also screened for potentially relevant research. The final selection was independently carried out by the principal investigator (NN) and the co-authors after reading the complete articles and the results were compared for agreement. Studies were eligible for inclusion if they met the following criteria: (a) performed in SA, (b) children and/or adolescents with special health needs/disability, (c) assessed oral health by quantitative measurement or qualitatively as reported by a parent or caregiver, (d) the decayed, missing and filled teeth index (dmft for primary and DMFT for secondary teeth) was used to assess caries severity. Only articles published in English were included. Unpublished manuscripts and grey literature were excluded. The results of the search, selection process and the number of studies included and excluded at each stage are shown in Figure 1.

Table I: Data extraction tool

Author(s)	
Year of study	
Study objective	
Study setting	
Study design	
Study population and sample size	
Type of SHCN/disability	
Key findings	
Critique	

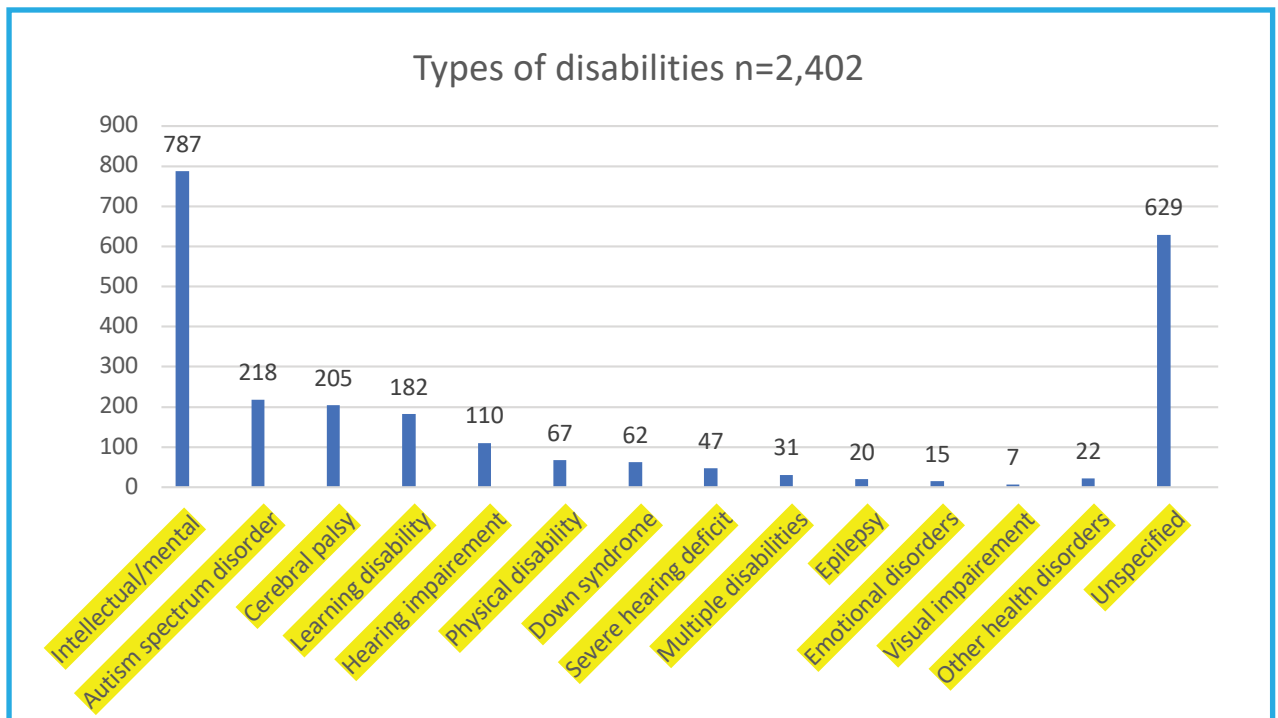
### Ethical considerations

Approval to conduct the study was obtained from the University of Witwatersrand Human Research Ethics Committee (Clearance number M220266).

## STUDY FINDINGS

### Characteristics of the identified studies

A total of 26 articles were retrieved, 20 of which did not meet the eligibility criteria. The reasons for excluding these articles were (i) participants were not CWSHCN, (ii) the study was conducted outside the review period or (iii) outcome other than dental caries. The six studies that were included in this review were cross-sectional in design and most participants



**Figure 2.** Types of disabilities among CWSHCN.

were from public special needs schools. The studies were conducted in urban and peri-urban settings except for one in a rural setting, thereby representing different socioeconomic backgrounds of the study participants in SA.<sup>25</sup>

#### Characteristics of the study participants

A total of 2,402 individuals with special healthcare needs were included in the review, 59.7% (n=1,433) of whom were male and 40.3% (n=969) were female. The age of the children ranged between 0 and 20 years. One study used caregivers of CWSHCN as a proxy of their child's oral health status.<sup>26</sup>

#### Types of disabilities

The types of disabilities varied across the studies. Among the disabilities included, inter alia, ID/MD n=787, CP n=205, LD n=182, ASD n=218, HI n=110, PD n=67, DS n=62, severe HI=47, EP n=20, "complex/multiple disabilities" n=31, VI n=7, ED n=15 and other health disorders n=22 as shown in Figure 2. The type of disability among the 629 children with special needs in one rural setting was not recorded. A descriptive summary of the articles is presented in Table 2.

#### Oral health status of CWSHCN

Poor oral health among CWSHCN was observed in all studies presenting as caries and/or gingivitis. The prevalence of caries among CWSHCN ranged from 22.5% to 85.2%.<sup>27, 28</sup> The mean dmft/DMFT scores ranged from 0.95 (SD 2.36) to 5.51 (SD 2.1)<sup>25, 27</sup> and 0.67 to 10.24 (SD 2.97)<sup>25, 29</sup> for the primary and permanent dentition, respectively. The studies reported high UTNs and mostly constituted untreated caries among the study participants of between 68%<sup>30</sup> and 100%,<sup>26</sup> attributed to low restorative care.

One study found that over half of the parents (56.7%) of CWSHCN rated their child's oral health status as average,<sup>26</sup> despite the high UTNs among the study sample. Furthermore, most caregivers (61%) of CWSHCN did not perceive the oral problems in their child as having an impact on overall health.

Two studies included a gingival health assessment and reported between 46% and 69% presence of gingival inflammation among children with ASD and ID, respectively.<sup>28,30</sup> One study reported plaque index as visible plaque in 43.6% of children with ASD.<sup>28</sup>

Other notable oral findings included mild loss of enamel (47%) and soft tissue trauma (lip biting) (25%) among children with ASD.<sup>28</sup> Orthodontic need for the correction of malocclusion were reported in 29% of children with ID.<sup>30</sup> However, the study did not elaborate on the types of occlusal disharmony in the study sample.

#### DISCUSSION

The characteristics and status of oral health among CWSHCN in SA between 2002 and 2023 were reviewed. Only six studies among CWSHCN were relevant, highlighting the paucity of data in SA. However, our review shows that the status of oral health for approximately 2,402 CWSHCN, aged between 0 and 20 years, were evaluated in the past two decades. Of the total sample in the six studies reviewed, 59.7% were male and 40.3% were female. According to the 2011 census, the prevalence of disability in SA was 7.5%<sup>31</sup> and more than 600,000 children aged between 5-14 years had a disability. Notably, due to the lack of current epidemiological data, the number of children with disabilities in SA is largely unknown. The NCOHS conducted between 1999-2002<sup>23</sup> reported that 39.7% of the 6-year-old age group were caries-free; however, this survey did not include CWSHCN. Furthermore, the figure was below the 50% goal set by the SA Department of Health (DoH) for the year 2000.<sup>32</sup>

Our study findings showed that the types of disabilities included, inter alia, intellectual disabilities (ID), Down Syndrome (DS), autism spectrum disorder (ASD), cerebral palsy (CP), epilepsy (EP), learning disabilities (LD), hearing impaired (HI), physical disabilities (PD), visual impairment (VI), emotional disorders (ED) and "complex/multiple disabilities". This list, however, did not include all CWSHCN defined as "...living with or at risk of chronic physical, developmental

Table II: Descriptive summary of the studies reviewed

Author	Year	Objective	Design	Sample (n)	Type of SHCN/ disability	Study setting	Results
Yengopal <i>et al</i>	2012	To determine the caries prevalence and UTN of children with special needs and compare with data from NCOHS	Cross-sectional analytic study	882 children (3-18 years) (65% male) mean age 10.5 years	Cerebral palsy (CP) (18.5%) hearing impaired (HI) (11.2%), learning disabilities (LD) (19.4%) and mental disability (MD) (51%)	Five special needs schools in Johannesburg (urban)	<ul style="list-style-type: none"> <li>Prevalence of caries: primary dentition – 27.55%, permanent dentition – 33.56%</li> <li>More than 80% UTNs</li> <li>dmft score 1.35 (LD) – 3.4 (CP)</li> <li>DMFT score 0.67 (HI) – 1.27 (MD)</li> </ul>
Nemutandani <i>et al</i>	2013	To determine the prevalence of dental caries among disabled individuals attending special schools in Vhembe districts.	Cross-sectional descriptive study	629 individuals with special needs (46% males) 0-6, 7-10, 11-18 and 19+ years	Disability not specified	Four special schools in Vhembe district, Limpopo (rural)	<ul style="list-style-type: none"> <li>Prevalence of caries – more than 80% in all age groups.</li> <li>dmft score under 6 years – 5.51 (SD 2.1)</li> <li>DMFTs of the 11-18 years – 7.38 (SD 3.22) and above 19 years – 10.24 (SD 2.97).</li> <li>High UTNs, &lt; 1% restorative care</li> </ul>
Roberts <i>et al</i>	2016	To assess the dental needs of a group of children with intellectual disability (ID) attending six special educational facilities in Cape Town, SA	Cross-sectional study	157 children with ID (67% males) mean age 10.1 years	Intellectual disability (ID)	Six special educational facilities in Cape Town (urban)	<ul style="list-style-type: none"> <li>Prevalence of dental needs:</li> <li>Gingival disease (69%)</li> <li>Untreated dental caries (68%)</li> <li>Malocclusion requiring orthodontic correction (29%)</li> </ul>
Naidoo and Singh	2018	To investigate the oral health status of children with ASD aged between 7-14 years in KwaZulu-Natal, SA	Investigative cross-sectional quantitative study	149 children with ASD (71.1% males), 7-8, 9-10, 10-11 and 12-14 years	Autism spectrum disorder (ASD)	Special needs schools in KwaZulu-Natal (78% peri-urban)	<ul style="list-style-type: none"> <li>Overall caries prevalence – 85.2%.</li> <li>DMFT score – 3.42</li> <li>Molars – 50% of score</li> <li>UTNs – 68.5%</li> <li>Soft tissue trauma with lip biting – 25%.</li> <li>Mild gingival inflammation – 46.3%</li> </ul>
Nqobco <i>et al</i>	2019	To assess how caregivers of CWSHCNs perceived the contribution of OHRQoL to the quality of life of these children	Survey of caregiver OHRQoL and child's oral health status	Convenient sample of 150 caregivers (mean age 39.5) and child pairs (mean age 8.7 years) (59.3% males)	Down syndrome (DS) (41%), CP (28%), ASD (10%), epilepsy (EP) (10%), complex disabilities (10%) and unknown (1%)	Down Syndrome Association (DSA) outreach sites in Johannesburg (urban)	<ul style="list-style-type: none"> <li>Overall caries prevalence – 42%</li> <li>56.7% of caregivers rated child's oral health as average</li> <li>Untreated caries (93-100%) regardless of disability type</li> </ul>
Gumede <i>et al</i>	2023	To determine the prevalence of dental caries among learners with disabilities attending special schools education in the eThekweni district	Cross-sectional descriptive study design	435 children with disabilities (62.3% male) mean age 13 years	ID (41.8%), physical disability (PD) (15%), ASD (12.4%), severe HI (10.8%), HI (2.5%), multiple disabilities (3.7%), LD 2.5%, visual impairments (VI) 1.6%, emotional disturbances (ED) 3.4%, other health impairments 6.2%	22 special schools in eThekweni (60% peri-urban and 27.1% urban)	<ul style="list-style-type: none"> <li>Prevalence of caries: Primary dentition – 22.5%, permanent dentition – 53.6%, DMFT – 1.97 (SD 2.36)</li> <li>D-88%, F-4%, M-9%</li> <li>dmft-0.95 (SD 2.36)</li> <li>Decay component – 99%</li> <li>Highest caries prevalence in ID – 46.4%</li> <li>dmft/DMFT increase with age (p=0.01)</li> </ul>

CWSHCN: children with special health care needs OHRQoL: oral health related quality of life UTN: unmet treatment needs dmft/DMFT: decayed, missing, filled teeth for deciduous and permanent teeth respectively

and behavioural conditions...".<sup>5</sup> Our study did, however, reflect the categories of disabilities provided in the 2011 SA census where the International Classification of Functioning Disability and Health<sup>33</sup> was used to categorise disability according to six functional domains: sight, hearing, communication, remembering/concentrating, walking and self-care. Using census data may have some limitations, for example parents are used as proxies to report on children with disabilities,<sup>34</sup> leading to possible underreporting. In addition, the use of functional domains may have resulted in the exclusion of children living with milder disabilities or chronic medical conditions who also form part of the diverse group of CWSHCN.

Our review found that caries prevalence among CWSHCN ranged between 22.5% and 85.2%. In addition, the caries severity reported by the dmft/DMFT scores varied across the disability groups and age categories. Caries severity appeared to increase with the age of the child in keeping with the impact of increased exposure to fermentable carbohydrates on dental caries development over time, and inadequate oral hygiene. Maintenance of oral hygiene is challenging for CWSHCN. For example, children with ASD display behavioural problems during routine tooth brushing while children with severe ID may lack the cognitive and manual dexterity to perform tooth brushing and rely on the parent/caregiver for assistance. Caregivers may be overburdened by the demands of caring for such children especially with poor support which is common in low resource settings.<sup>35</sup> Although the severity of the disabilities was not recorded in the studies reviewed, it is likely that SA children with more severe cognitive or behavioural problems may have had higher dmft/DMFT scores in keeping with the results of a study in India where children with severe ID had higher DMFT scores.<sup>36</sup> Identifying CWSHCNs who are at greater risk of dental caries and instituting early preventative measures may prevent the cumulative burden of dental caries over time.

Dental caries in children largely remains untreated. In 2010, untreated caries in the deciduous dentition was the 10th most prevalent condition affecting 9% of the global population.<sup>37</sup> Furthermore, the condition is even more prevalent in many low- and middle-income countries (LMICs).<sup>17</sup> In SA, more than 80% of caries in children in the last NCOHS was not treated.<sup>23</sup> More than two decades later, our review has shown significant UTNs among CWSHCN as reflected by the high "decay" component of the dmft/DMFT scores. Similarly, high UTNs have been reported among CWSHCN in other LMICs such as Brazil, India, Nigeria and Rwanda.<sup>38-41</sup> Some of the reasons for high UTNs were low utilisation of oral healthcare services,<sup>40</sup> transportation difficulties,<sup>42</sup> financial constraints of parents, reluctant dental providers and behavioural challenges of CWSHCN in the dental setting.<sup>43</sup> In a systematic review of the determinants of dental caries among children residing in North Africa and the Middle East, the interplay of child characteristics, family background, diet and oral hygiene habits influenced oral health in children.<sup>44</sup> Thus, barriers related to the child's special need/disability, family socioeconomic status and the environment may hinder access to preventative and restorative treatment for CWSHCN, especially in LMICs. These barriers suggest that a multifaceted approach is required to address the oral health inequalities and improve access to dental care. All stakeholders involved in children's health need

to prioritise oral health for CWSHCN, especially for those from disadvantaged backgrounds. Policy guidelines need to address contextual issues related to poor oral health for this population group in both developing and developed countries. To this end, the South African government has shown a commitment to provide universal health coverage through the National Health Insurance (NHI) Bill, and improve access to quality healthcare to previously disadvantaged groups.<sup>45</sup>

Two studies in SA reported poor oral hygiene among children with ID and ASD.<sup>28,30</sup> Similar findings were reported in Nigeria among 5- to 19-year-old children where significantly poorer oral hygiene was found in children with special needs compared to healthy children.<sup>40</sup> Globally, poor oral hygiene has been reported among children with ID,<sup>2</sup> resulting in gingivitis.<sup>46</sup> Gingivitis can resolve with improved oral hygiene; however, when left untreated it may progress to periodontitis, a chronic inflammatory disease of the dental supporting structures. Periodontitis, in turn, increases the risk for the development of noncommunicable diseases such as diabetes and cardiovascular diseases.<sup>47</sup> Thus, it is vitally important to maintain good oral health in CWSHCN for both oral and general health.

In this review, other reported oral health problems among CWSHCN in SA included malocclusion (29%)<sup>30</sup> and soft tissue trauma (25%)<sup>28</sup>. A 1994 SA study found that 74.5% of the 381 children with disabilities needed orthodontic treatment.<sup>48</sup> Similarly, a high prevalence of malocclusion was found among children and adolescents with mental disabilities in India.<sup>49</sup> Occlusal disharmony may be more prevalent among certain groups of CWSHCN such as spastic CP, in whom an imbalance of the orofacial muscles may result in constriction of the dental arches, a posterior cross bite and an anterior open bite.<sup>11</sup> Furthermore, patients with malocclusion characterised by protrusion of maxillary permanent incisors are more prone to traumatic dental and soft tissue injuries.<sup>50</sup> Among the risk factors associated with malocclusion in children with CP include mouth breathing and lip incompetence.<sup>51</sup> Thus, there is a need to incorporate orthodontic treatment in children with milder forms of disabilities to improve their quality of life.

The oral health status of CWSHCN may affect their overall quality of life.<sup>52</sup> Untreated dental caries may affect the ability to eat, drink and sleep without discomfort or pain.<sup>53</sup> Developmental delay may affect speech and cognition making it difficult for the children to express discomfort or the feeling of pain.<sup>54</sup> However, despite evidence pointing to the negative impact of poor oral health such as severe dental caries on the quality of life among CWSHCN,<sup>55</sup> one study in SA reported contradictory findings where 61% of caregivers of CWSHCN did not consider the oral condition in their child to impact overall health.<sup>26</sup> The chronic medical condition of the child or disability may be more of a priority due to its impact on morbidity. Dental caries in the absence of pain, discomfort or sleep disruption may not be perceived as negatively affecting the child and needing attention. Caregivers' perceptions may be related to their socioeconomic status (SES) as children from families with high SES and parental education had better oral health-related quality of life.<sup>56</sup> Hence, contextual factors, especially in resource constrained settings, may influence the extent to which untreated dental caries among CWSHCN is perceived to impact overall quality of life.

Access to healthcare is a key global goal on the development agenda. The United Nations Millennium Development Goals (MDGs) in 2000 and later the Sustainable Development Goals (SDGs) and, more specifically, SDG3, committed to “ensure healthy lives and promote wellbeing for all at all ages”.<sup>57</sup> Among the goals of the National Oral Health Policy in SA is the promotion of oral health and increased access to services. However, the policy is outdated and in need of review based on current epidemiological data.<sup>58</sup> The inclusion of CWSHCN, who may be more at risk for dental diseases, would be important to provide specific strategies for the prevention and treatment of oral diseases and increase access to services in line with the NHI Bill. In addition, an integrated maternal and child oral health policy aimed at increasing access to oral health services for mothers and children could reduce the oral disease burden among children and those with special needs.<sup>59</sup> SA has been successful in creating an enabling environment for policy development work in the field of disability.<sup>60</sup> However, policy implementation has faced challenges of capacity constraints, low resource allocation and lack of government commitment. In a review of the National Oral Health Policy in SA, Mukhari-Baloyi et al<sup>58</sup> noted that the policy goals were clear but strategies for implementation were not well understood. Hence, more needs to be done to translate policies on people with disabilities to accessible and comprehensive healthcare that includes oral health, in developing countries such as SA, to promote equity and reduce inequalities.

Despite significant socioeconomic reforms in SA in the past two decades,<sup>61</sup> inequalities in health, including oral health, for people with disabilities persist.<sup>61</sup> Factors related to poverty such as unemployment, low literacy and inadequate access to healthcare have a greater negative impact on South African individuals living with disabilities.<sup>62</sup> In SA, children with disabilities, particularly from low-resource settings, may face challenges accessing basic services such as health and education. For example, in a group of 156 children with disabilities from a small town near Soweto in SA, few were able to access basic education, assistive devices and social grants.<sup>63</sup> The situation appears not to have improved significantly in post-apartheid SA. In one qualitative study, caregivers of children with ID from a small town in SA reported financial difficulties, poor care networks and community stigma as barriers to utilisation of specialised hospital services.<sup>64</sup> Apart from individual caregiver and community barriers, system level barriers have been cited. For instance, a scoping review found that among children with disabilities living in LMICs in sub-Saharan Africa, poor policy implementation, lack of physical access and inadequately trained health professionals were barriers to healthcare access.<sup>65</sup> These factors may affect the quality of life of not only the children with disabilities but also their families. Therefore, addressing the wider social and economic disparities affecting health and healthcare access may lead to better oral and general health for children with disabilities in SA.

## STRENGTHS AND LIMITATIONS OF THE STUDY

Our review focused on the status of oral health among CWSHCN in SA over the past two decades. Among the limitations were, first, the availability of only a few studies. The exclusion of unpublished studies may have resulted in publication bias. Second, the exclusion of studies that did

not report dental caries as an outcome may have led to selective outcome reporting bias. Among the strengths of the review was the use of a standard literature review method and DET, thereby decreasing the risk of bias. In addition, the review included participants with various special healthcare needs and not individual categories of disabilities, thereby increasing the sample. Finally, the studies were conducted in different geographical and socioeconomic settings in SA, possibly providing different contextual factors related to the oral health of CWSHCN and enhancing generalisability of the results within SA.

Despite the limitations, the review offers useful insights into the lack of data related to the status of oral health among CWSHCN in SA. In addition, the review has consolidated data on the characteristics and status of oral health among CWSHCN in SA over the past two decades. The data are important in understanding the oral health needs of this vulnerable group and to plan strategies to improve oral health, oral health outcomes and reduce inequalities in line with the SDGs call to “leave no one behind”.<sup>57</sup>

## CONCLUSION

Poor oral health and high UTNs were prevalent among CWSHCN in SA, with little evidence of preventative and restorative care. There was insufficient published data on the status of oral health among CWSHCN in SA.

## RECOMMENDATIONS

There is a need for a nationwide survey to determine the oral health status of CWSHCN in SA, to enable proper planning of preventative and comprehensive oral healthcare. Future research should focus on identifying the barriers to accessing early preventative and restorative care. Increasing awareness of the importance of good oral health for CWSHCN among all stakeholders involved with children could facilitate early referrals for preventative and restorative care.

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## CPD questionnaire on page 120

The Continuing Professional Development (CPD) section provides for twenty general questions and five ethics questions. The section provides members with a valuable source of CPD points whilst also achieving the objective of CPD, to assure continuing education. The importance of continuing professional development should not be underestimated, it is a career-long obligation for practicing professionals.

