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LITERATURE REVIEW



Oral health status and reported oral health problems in people with intellectual disability: A literature review

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ABSTRACT

Background: People with intellectual disability (ID) experience poor oral health and are at greater risk of dental decay and periodontal diseases. This impacts on their general health and wellbeing. This review summarises the research literature about oral health status and contributing factors to poor oral health

Method: We conducted a literature review using “intellectual disability” and “oral health” as our two core areas of focus.

Results: People with ID had poorer oral health, greater numbers of tooth extractions, more caries, fewer fillings, greater gingival inflammation, greater rates of endentulism, and had less preventative dentistry and poorer access to services when compared to the general population. Anxiety during dental procedures was a key issue for females with ID.

Conclusions: Further research is needed to identify, pilot and test appropriate and effective interventions that can reduce this preventable health disparity. The design of an ID-specific dental anxiety scale is another priority.

KEYWORDS

Oral health; health disparities; dental services; gender; intellectual disability; dental anxiety

Oral health is defined as the ability to speak, smile, smell, taste, touch, chew, swallow and convey a range of emotions through facial expressions with confidence and without pain, discomfort and disease of the cranio-facial complex (Glick et al., 2016). Evidence is continually emerging that shows poor oral health has a detrimental impact on general health, and is significantly associated with major chronic diseases such as cardiovascular disease, diabetes, respiratory disease and stroke (Aida et al., 2011; Genco, Glurich, Haraszthy, Zambon, & DeNardin, 2001; Joshipura, Hung, Rimm, Willett, & Ascherio, 2003; Jung, Ryu, & Jung, 2011; Walls & Steele, 2001). In addition, poor oral health has vast implications on quality of life, affecting an individual's psychological health, ability to socialise, feelings of social wellbeing, growth, appearance, speech, eating and enjoyment of life (Locker, 1997; Zucoloto, Maroco, & Campos, 2016). People with intellectual disability (ID) can experience many challenges that could affect their oral health status, including the need for assistance with core activities, barriers to accessing quality health care, and a higher likelihood of having lower incomes and education levels when compared to the general population (Kavanagh, Krnjacki, & Kelly, 2012). It is well documented that people with low income and education levels seldom

access oral health services and as a result have higher rates of dental decay and missing teeth (Chrisopoulos, Harford, & Ellershaw, 2016).

Research has shown that poor oral health is one of the most common secondary conditions affecting people with ID (Traci, Seekins, Szalda-Petree, & Ravesloot, 2002). This population group has a higher prevalence and greater severity of periodontal diseases such as gingivitis and periodontitis, compared to people without ID. Further, the levels of untreated dental decay are consistently higher in this population with several studies showing more missing and decayed teeth but less filled teeth in people with ID (Anders & Davis, 2010). Factors that contribute to poor oral hygiene among people with ID include inadequate brushing technique and a lack of caregiver training. Anders and Davis suggest that strategies to counter this include added training for dentists, more prevention strategies, and interventions to increase tolerance of routine oral care.

Dental anxiety has also long been identified as a major barrier to accessing services for a range of vulnerable population groups, such as people with ID (Gordon, Dionne, & Snyder, 1998). Therefore, it is essential to gain a comprehensive understanding of the oral health of people with ID, to inform the development of

strategies and interventions to address the oral health issues in this population and thereby improve their quality of life and general health. However, to date, there has only been one systematic review conducted regarding ID and oral health, which only examined published reports comparing the differences between the oral health of people with and without ID (Anders & Davis, 2010). There are no existing reviews that have focussed exclusively on the oral health status of people with ID, or suggested interventions and strategies to improve their oral health.

Aims

The aim of this review is to provide a descriptive summary of the oral health status and oral health problems in people with ID to identify ways to bring together the oral health and ID specialists to develop a future research and policy agenda. Gaining an insight into the extent of the problem and contributing factors will inform future exploratory and intervention studies that seek to improve the oral health status of and develop better oral health outcomes for people with ID.

Methodology

Our two core areas of focus for this literature review were “intellectual disability” and “oral health”. Databases searched included Cochrane, CINAHL, PubMed, Medline, ScienceDirect and Scopus with the search conducted on the 5th of December 2016. The following search terms were used in conjunction with various Medical Subject Headings: Intellectual Disability; Health Services for Persons with Disabilities; Mentally Disabled Persons; Learning Disorders; Developmental Disabilities; Cognition Disorders; Oral Health; Dental Care for Disabled; Dental Caries; Tooth Diseases; Oral Hygiene; Preventive Dentistry; Mouth Care; “mental* retard*” OR “intellectual disabil*” OR “learning disabil*” OR “developmental disabil*” OR “cognitive disabil*” OR “intellectual impairment” OR “mental deficiency” OR “mentally defective” OR “psychosocial retard*” OR “oral health” OR “dental” OR “caries” OR “oral hygiene” OR “preventative dentistry” OR “mouth care”. The reference search was limited to articles published between 2000 and 2016 and those written in English, as we assumed there would be limited published literature, and we had no access to or budget for translation services if we did find publications in languages other than English.

The initial search yielded 998 results that met the inclusion criteria: our search stated terms, published between 2000 and 2016, and written in English. After duplicates were removed we excluded papers at the

title and abstract level that reported on cognitive impairment other than ID, animal studies, aetiology reports, individual case studies, systematic reviews, special needs other than ID, opinions and perspectives, and autism spectrum without ID. After this process, there were no oral health exclusion criteria required as all remaining papers were about oral health. This search process left 141 papers to be screened at the article level which were reviewed by the first and second authors. Our exclusion criteria at the article level were the same as at the title and abstract levels and this left a total of 63 papers to be included in the final review. Our initial review categorised papers into those ($n = 36$) that only reported *oral health status and problems* (e.g., descriptive surveys, record reviews and dental screening studies) and those ($n = 27$) that provided some insight into *solutions for those problems* (e.g., caregiver studies, interventions and policy papers). This manuscript reports only on the first of these two categories: the oral health status and reported problems in people with ID. The second of these two categories is the focus of a separate manuscript. [Figure 1](#) provides a descriptive overview of the search and exclusion process.

Results

[Table 1](#) provides a descriptive summary of all 36 articles giving a rich insight into the studies aims, the methods used, the participants and key results from each study. To summarise, there are large levels of unmet oral health needs in people with ID who appear to have a much poorer oral health status than people without ID, which includes high levels of untreated decay and gum disease. Most importantly, these studies confirm that many people with ID rely either fully or partly on caregivers for their oral health needs suggesting that caregiver training is an important factor for oral health programs. Seven studies reported results from the *Special Olympics-Special Smiles*, dental screening program (incorporating participants from Germany, Italy, the USA, the UK, Latin-America, the Caribbean, Poland, Romania, Slovenia and Indonesia). Although there was a very wide distribution of studies from around the world, the USA represented the largest number of studies ($n = 9$) followed by Japan and Italy ($n = 4$), and then Brazil and the UK ($n = 2$). The majority of studies were cross-sectional screening studies using convenience samples ($n = 29$) with a small number of retrospective case file reviews ($n = 6$). Only the study by Mac Giolla Phadraig et al. (2015) used a representative population-based dataset; the TILDA dataset from Ireland. There were two studies, one Swedish (Gabre, Martinsson, & Gahnberg, 2001) and one Japanese (Idaira et al., 2008)

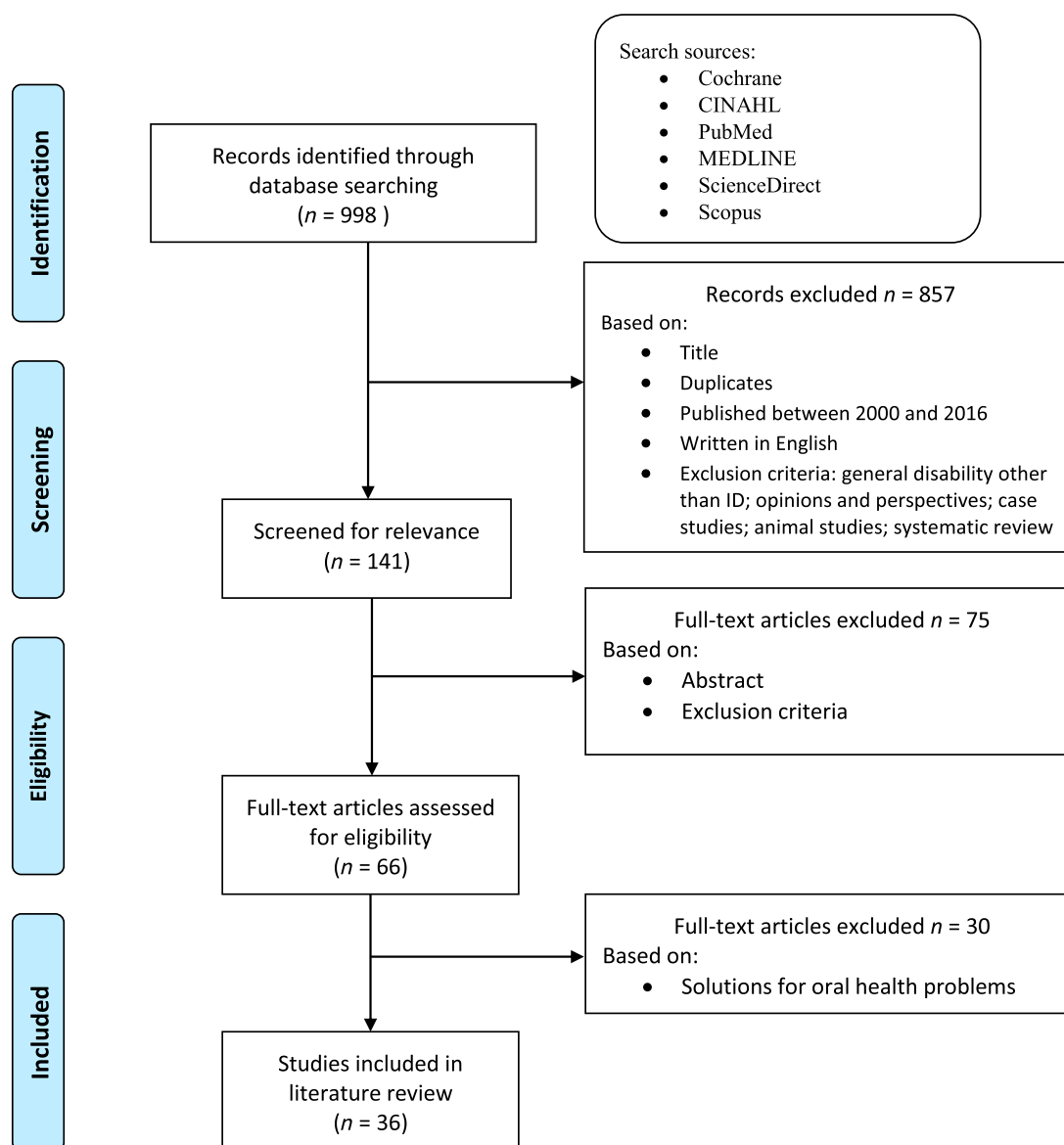


Figure 1. Literature search and review flowchart.

that utilised a longitudinal design and were, therefore, able to track participants over time. Regarding participants' ages, there was an even distribution of age groups across all of the studies.

In total, there were 23,181 participants with ID across all studies; when excluding the four studies (Ahuja et al., 2016; Finkelman et al., 2014; Hanke-Herrero et al., 2013; Moreira et al., 2012) where participants' gender was not reported from this total ($n = 21,942$) there was an estimated total of 13,257 male participants representing 58% of the total population of participants with ID. Although most studies did report gender and some used gender as an independent variable in their analyses, there were few gendered differences to report. In the Italian study assessing dental anxiety by Fallea et al. (2016),

females with ID were more significantly likely to experience anxiety when compared to males with ID. The USA study by Lindemann et al. (2001) reported that males with ID were more likely to have fair or poor oral health compared to females with ID. By contrast, the study by Liu et al. (2014) on Chinese participants with ID reported that being female was associated with having dental caries.

Two studies (Cumella et al., 2000; Fallea et al., 2016) explored the prevalence of dental anxiety and concern upon visiting a dentist, and identified dental anxiety as a major factor influencing the oral health of people with ID. Both studies found a significant level of dental anxiety among people with ID. Fallea et al. explored correlations of dental anxiety with other demographic

Table 1. Descriptive summary of review articles, in alphabetical author order.

Authors, year (country)	Design and analysis	Objective	Population	Key findings
Ahuja et al. (2016) (India)	Cross-sectional study	To evaluate differences between paediatric patients with and without ID who underwent dental treatment under GA	480 patients (with ID $n = 350$, without ID $n = 130$) who underwent dental treatment under GA between 2008 and 2014	Paediatric patients with ID have a higher frequency of tooth extraction and restorative treatment NB: gender of participants not reported
^b Bissar, Kaschke, and Schulte (2010) (Germany)	Cross-sectional study	To determine the caries prevalence and oral hygiene habits in German adolescent athletes with ID participating in the German Special Olympics games 2008	160 adolescent athletes with ID (males $n = 102$, females $n = 58$) aged between 12 and 17 years (mean age 15.3 years)	<ul style="list-style-type: none"> • Caries prevalence was 58.1% and the mean <i>DMFT</i> was 2.3 • The mean number of fissure-sealed teeth was 2.5 • About half of the participants showed signs of gum inflammation and a higher proportion of children living at home had untreated caries when compared to those living in an institution • More than 90% brush teeth by themselves without assistance
Chang, Lee, Son, and Kim (2014) (Korea)	Case-control study	To explore if the caries risk profile of patients with ID would be different than that of dental patients without a disability and to identify any factors contributing to caries risk	102 patients with ID (males $n = 68$, females $n = 34$; mean age 23.8) and 100 patients without ID (males $n = 51$, females $n = 49$; mean age 23.19 years)	<ul style="list-style-type: none"> • Mean chance of avoiding caries in the ID group was significantly lower than in the non-ID group • The ID group had significantly higher numbers of decayed and missing teeth, but fewer filled teeth than the non-ID group • Risk of future caries was closely associated with insufficient oral hygiene behaviours
Chi et al. (2010) (USA)	Cross-sectional study	To compare preventive dental utilisation for children with intellectual and/or developmental disability (IDD) and those without IDD and to identify factors associated with dental utilisation	4385 children with IDD aged between 3 and 17 years (male $n = 2744$, female $n = 1641$) and 103,220 children without IDD (males $n = 52,815$, females $n = 50,405$)	<ul style="list-style-type: none"> • Significantly more males in the IDD group compared to the non-ID group • Significantly higher proportion of non-IDD children received preventive care than those identified as IDD (48.6% vs. 46.1%), • Final regression model that adjusted for covariates revealed no statistically significant difference between the two groups
Chi, Momany, Jones, and Damiano (2011) (USA)	Cross-sectional study	To evaluate the relationship between having IDD and the timing of the first dental visit for children newly enrolled in Medicaid in Iowa	5391 children aged 3–8 years with IDD ($n = 96$; male $n = 65$, female $n = 31$) and without IDD ($n = 5295$; male $n = 2683$, female $n = 2612$)	About 32% of children had a first dental visit within six months of enrolment. After adjusting for covariates, children with IDD were 31% more likely to have a delayed first dental visit ($p = .04$)
Cumella, Ransford, Lyons, and Burnham (2000) (UK)	Case-control study	After changes to UK dental service provision in the 1990s, this study sought to assess the extent of unmet clinical needs and perceptions of oral hygiene in a group of adults with ID who were not in contact with the community dental service	Interviews with 60 adults with ID (male $n = 33$, female $n = 27$); 50 of these underwent oral health screening	<ul style="list-style-type: none"> • High levels of untreated caries (decay), and gingival or periodontal (gum) problems. Participants were largely unaware of dental problems, and used the appearance and absence of pain to judge the condition of their teeth • Adults with ID depended on caregivers for oral health decision-making and support • Training towards carers and personal skills in communication and attitudes of dentist when caring people with ID could be improved
de Jongh, van Houtem, van der Schoof, Resida, and Broers (2008) (The Netherlands)	Cross-sectional study	To assess the oral health status, treatment needs and barriers to dental care of noninstitutionalized children with severe ID	61 children with ID (males $n = 37$, females $n = 24$) aged 4–12 years (mean age 7.7 years) were screened. 126 caregivers and 40 dentists completed descriptive survey	<ul style="list-style-type: none"> • 57.4% had untreated caries (mean <i>DMFT</i> = 3.0, <i>SD</i> = 3.1) with the proportion of caries-free children at 29.5% • Caregivers considered the noncooperation of children with ID as the most troublesome aspect of their daily oral care • Dentists considered communication problems as the most important barrier to treatment
^b Dellavia, Allievi, Pallavera, Rosati, and Sforza (2009) (Italy)	Cross-sectional study	To examine the systemic health and oral health status Italian Special Olympics athletes with ID in order to determine the amount of untreated caries and dental restorative need	341 athletes with ID (aged 16–65 years) had oral health screening; DS group (males $n = 108$, females $n = 63$) and ID, but no DS group (males $n = 92$, females $n = 78$)	<ul style="list-style-type: none"> • Most of the participants had good systemic health, but oral health status was worse when compared to similar studies based at the Special Olympics from around the world

Donnell, Sheiham, and Wai (2002) (HK, China)	Cross-sectional study	To identify the dental needs and oral health status of children and adults with ID	748 participants (male $n = 431$, female $n = 317$) with disabilities (only 34 did not have ID) grouped into three age categories: 4 years (male 191, female 118), 14 years (male $n = 103$, female $n = 71$) and 25–35 years (male $n = 137$, female $n = 128$)	<ul style="list-style-type: none"> Decayed and filled teeth were significantly more frequent in athletes who had ID, but did not have DS compared to those with DS No significant differences were found between the two groups in the number of subjects with filled, sealed, or traumatised teeth Mean <i>DMFT</i> scores by age groupings were 1.25, 2.27 and 5.23, respectively There was no correlation between caries experience and physical mobility, ID, or gender in any age group
^a Dourado, Andrade, Ramos-Jorge, Moreira, and Oliveira-Ferreira (2013) (Brazil)	Cross-sectional study	To evaluate the association between executive or attentional functions and teeth with cavities due to caries in individuals with and without CP	76 children with CP and 89 children without neurological impairment (male $n = 83$, female $n = 82$) aged between 7 and 12 years (mean age 8.9 years)	<ul style="list-style-type: none"> No significant association was found between the number of teeth with cavities due to caries and socioeconomic status The number of teeth with cavities due to caries was significantly higher in the CP group A better performance on executive function tasks was associated with a lower number of teeth with cavities due to caries
Fallea, Zuccarello, and Cali (2016) (Italy)	Cross-sectional study	To investigate the prevalence of dental anxiety in a population of patients with borderline intellectual functioning (BIF) and patients with mild and moderate ID, and how dental anxiety correlated with their age and gender	700 patients (male $n = 413$, female $n = 287$) referred for diagnostic and rehabilitation services. Participants with BIF $n = 270$, mild ID $n = 330$, and moderate ID $n = 100$. Ages ranged from 6 to 47 years	<ul style="list-style-type: none"> Moderate Anxiety was the most prevalent dental anxiety category for patients with BIF (15.56%) and mild ID (18.79%), while severe anxiety was the most prevalent category for patients with moderate ID (21%) A statistically significant difference in anxiety ($p < .001$) between the three groups was found There were also significant correlations between being older and decreased anxiety ($p < .001$) and being female and increased anxiety ($p < .001$)
^b Fernandez et al. (2012) (USA)	Cross-sectional study	To describe the oral health of special Olympics athletes with ID at the annual Special Olympics Metro Tournament in New York City between 2005 and 2008	664 people with ID (male $n = 386$, female $n = 278$) with a mean age of 26 years (range 6 to ≥ 60)	<ul style="list-style-type: none"> High preventative oral health needs in the study population when compared with norms in the general population 9% reported oral pain, 8% needed caries, 60% had filled teeth, and 32% had signs of gingival disease Mouth guards were recommended for 26% of athletes The prevalence of untreated decay was 41% in Poland and 61% in Slovenia 70% of the Romanian athletes had signs of gingival disease and only 3.8% presented molar fissure sealants 47% of Polish athletes were in need of urgent treatment
^b Fernandez Rojas et al. (2016) (Poland, Romania and Slovenia)	Cross-sectional study	To describe the oral health of special Olympics athletes with ID at the Special Olympics in Poland, Romania and Slovenia between 2011 and 2012	A total of 3545 athletes with ID participated in the study. Poland ($n = 1569$; male $n = 1081$, female $n = 488$), Romania ($n = 1683$; male $n = 1011$, female $n = 672$) and Slovenia ($n = 293$; male $n = 187$, female $n = 106$)	<ul style="list-style-type: none"> Over time, there was a significant decrease in caries ($p < .001$) and a significant increase in periodontitis ($p = .002$) Associations between time and other outcome variables were not statistically significant NB: Participant's gender not reported
Finkelman, Stark, Tao, and Morgan (2014) (USA)	Case-control study	To evaluate how dental and oral health outcomes changed over time among patients with IDD	107 adults with IDD who were treated at the one dental clinic	<ul style="list-style-type: none"> The caries incidence was low, on average 0.51 new lesions per year Persons with mild ID experienced more caries than other subjects People who had lived in an institution had a lower caries incidence but a higher tooth mortality incidence During the 8.5 years, the subjects had lost on average 1.82 teeth, with periodontitis the main reason for tooth mortality Individuals who cooperated poorly with dental treatment had also lost the most teeth
Gabre et al. (2001) (Sweden)	Cohort study	To describe the longitudinal changes to the prevalence of caries, incidence of tooth mortality, and interproximal bone loss in adults with ID	124 adults with ID (males $n = 70$, females $n = 54$) aged between 21 and 40 years in 1990, were followed over an 8.5-year time span	

(Continued)

Table 1. Continued.

Authors, year (country)	Design and analysis	Objective	Population	Key findings
^b Hanke-Herrero, López Del Valle, Sánchez, Waldman, and Perlman (2013) (USA)	Cross-sectional study	To evaluate the oral health status and dental needs of the athletes with ID from Latin-American and Caribbean countries who were participating in the II Latin-American Special Olympics games held in Puerto Rico, 2010	445 athletes with ID from Latin-American ($n = 367$) and Caribbean ($n = 78$) countries; age range was 3–54 years (mean 24 years)	Untreated dental caries was recorded for more than half of the examined athletes. Missing teeth were noted in more than one-third of the athletes. More than half of the participants had signs of gingival disease and half needed preventive mouth guards. Statistics for each Latin-American country suggests a dissimilar trend of dental decay and treatment needs among nations. NB: gender of participants not reported.
Horie et al. (2014) (Japan)	Cross-sectional study	To investigate the presence of oral opportunistic pathogens (OOP) in people with ID as part of an aspiration pneumonia reduction strategy	31 patients with ID (male $n = 21$, female $n = 10$) who were resident at a welfare home for people with ID	OOPs were found in 61.3% of the patients, of which methicillin-sensitive <i>Staphylococcus aureus</i> (MSSA) was the most commonly detected (38.7%). A significantly high proportion of male patients were OOP-positive, and a significantly high proportion of patients were <i>Candida</i> sp.-positive.
Idaira et al. (2008) (Japan)	Cohort study	To investigate the specific factors related to the occurrence of dental caries and tooth extraction	189 patients with severe ID (male $n = 90$, female $n = 99$), with an age range of 8–75 years living in an institution where all oral hygiene was provided by nurses	Rumination and tube feeding were identified as significant factors associated with new dental caries. On the other hand, infancy or childhood impairment and drooling were identified as significant factors related to tooth extraction.
Kancherla, Van Naarden Braun, and Yeargin-Allsopp (2013) (USA)	Cross-sectional study	To examine the frequency of dental visits and selected associated factors that promote or limit dental visits among young adults with and without ID	244 young adults with ID (male $n = 144$, female $n = 100$) 124 young adults without ID (male $n = 56$, female $n = 68$)	<ul style="list-style-type: none"> • Frequency of dental visits during a year: Fewer than half (45.1%) of all young adults with ID reported visiting a dentist at least once per year, compared with 58.1% of young adults without ID. • Factors associated with not visiting a dentist during the year were: being male, black, low SES, having less than high school education, and having a toothache during the previous four weeks.
Khocht, Janal, and Turner (2010) (USA)	Cross-sectional study	To compare periodontal disease status of people with ID between participants with and without Down syndrome and a non-disabled matched comparison group	Three subject groups (217): Down syndrome ($n = 55$; male $n = 29$, female $n = 26$), ID non-Down syndrome ($n = 74$; male $n = 43$, female $n = 31$), and a matched comparison group ($n = 88$; male $n = 37$, female $n = 51$)	<ul style="list-style-type: none"> • Patients with DS and ID had higher levels of gingival inflammation and plaque than the comparison group. • Only the subjects with Down syndrome showed increased levels of periodontal attachment loss.
Lindemann, Zschel-Grob, Opp, Lewis, and Lewis (2001) (USA)	Cross-sectional study	To gain a comprehensive picture of oral health status of Lanterman Center population to determine if living situation influences oral health status	325 people with developmental disability (male $n = 174$, female $n = 179$), 84% had ID	<ul style="list-style-type: none"> • Being male was associated with having fair or poor overall oral health. • Persons who brushed their own teeth had fewer missing teeth than those who did not. • Persons with a dental record had fewer decayed and more filled teeth. • Persons living at home with family or friends had significantly lower DMFT index (better oral health) than those living independently or in residential facilities.
Liu et al. (2014) (Taiwan)	Cross-sectional study	To determine the factors associated with oral health behaviours and caries experience in children with ID living in China	450 children with ID (male $n = 308$, female $n = 142$)	<ul style="list-style-type: none"> • Children with ID had a prevalence of dental caries at 53.5% with fewer caries significantly associated with oral health behaviours (e.g., daily brushing and dental visits in preceding 12 months). • Having cerebral palsy and being female increased the odds of having dental caries.
Mac Giolla Phadraig et al. (2015) (Ireland)	Cross-sectional study	To describe and compare the reported dentate status and complete denture use of older people with and without ID in Ireland	478 participants with ID (male $n = 203$, female $n = 275$) from IDS-TILDA database matched with 478 people without ID (male $n = 190$, female $n = 288$) from TILDA database	<ul style="list-style-type: none"> • The proportion of the 478 IDS-TILDA participants with no teeth was higher than TILDA participants (34.1% vs. 14.9%). • Edentulism was prevalent earlier for those with ID. Notably, 61.3% of edentulous older people with ID were without dentures.

Moreira et al. (2012) (Brazil)	Cross-sectional study	To evaluate if the severity of ID is a factor that affects the development of dental cavities in patients with cerebral palsy (CP)	165 individuals from a physical rehabilitation centre. 76 were diagnosed with spastic CP, 89 had no disability and were used as a matched comparison group	<ul style="list-style-type: none"> Children with CP who presented with ID had a larger number of dental cavities than children with CP without ID and children in the general population
Morgan et al. (2012) (USA)	Cross-sectional study	To describe the patterns of oral health problems and capacity to cooperate in a dental examination	4732 adults with ID (male $n = 2714$, female $n = 2018$) who were receiving dental care through a state-supported system of dental clinics	<p>NB: gender of participants not reported</p> <ul style="list-style-type: none"> The prevalence of untreated caries in the study population was 32.2%, of periodontitis was 80.3% and of edentulism was 10.9% Only 25% of participants had the ability to accept dental intervention with the remainder in need of some behavioural assistance
Naka et al. (2009) (Japan)	Cross-sectional study	To investigate the risk of periodontitis by examination of 10 selected periodontopathic bacterial species in dental plaque specimens	187 children with ID, CP and autism (male $n = 136$, female $n = 51$) aged 1–6 years attending a day care centre	<ul style="list-style-type: none"> The most frequently detected species was <i>Capnocytophaga sputigena</i> (28.3%), followed by <i>Aggregatibacter actinomycetemcomitans</i> (20.9%) and <i>Campylobacter rectus</i> (18.2%) <i>Porphyromonas gingivalis</i> was not detected in any of the subjects 20% of participants were at greater risk of periodontitis
Oliveira et al. (2013) (Brazil)	Case-control study	To evaluate the oral hygiene, caries experience, treatment needs, and access to oral health services of young people with ID and their non-disabled siblings	103 young people with ID (male $n = 62$, female $n = 41$) who attended a special needs centre and 103 siblings (male $n = 42$, female, $n = 61$)	<ul style="list-style-type: none"> Those with ID had more decayed and missing teeth, fewer dental restorations, and had a greater need for tooth extraction than their siblings 30% of young people with ID had never received dental treatment and had difficulty accessing public health services
Peretz, Spierer, Spierer, and Rakocz (2012) (Israel)	Cross-sectional study	To investigate differences in dental disease, dental treatment, duration of GA sessions, and consequent hospitalisation between subject groups	46 participants had systemic diseases (SD) (male $n = 23$, female $n = 23$) and 75 had IDD (male $n = 45$, female $n = 30$) aged between 2 and 20 years who had received dental treatment under GA	<ul style="list-style-type: none"> Dental disease in the primary teeth was significantly higher among the group with SD In the permanent teeth, dental disease was higher among the group with IDD, though not significantly More teeth were restored, and total DMFT was significantly higher among subjects with SD In the permanent teeth, more extracted and more restored teeth and higher DMFT were noted among subjects with IDD, though not significantly Pulpectomies were significantly more prevalent among those with IDD
Petrovic et al. (2016) (Serbia)	Cross-sectional study	To examine the factors affecting oral health status among children and adults with ID referred to a university dental clinic	1000 children and adults with ID (males $n = 549$, females $n = 451$)	<ul style="list-style-type: none"> Odds ratios for caries were significantly higher among adult persons with ID and those with more severe ID Institutionalisation was associated with a 2.4 times greater odds of untreated decay Institutionalisation and co-occurring disabilities have been found to be significantly associated with a higher probability of developing gingivitis
Pradhan, Slade, and Spencer (2009) (Australia)	Cross-sectional study	To examine the caries experience of adults with ID depending on residential setting and care-related factors	Sample of 267 adults with ID (males $n = 165$, females $n = 102$) were drawn from a survey of caregivers of adults with ID	<ul style="list-style-type: none"> The prevalence of decay ($D > 0$) was 16.9% and 76.3% had caries experience ($DMFT > 0$) Care-recipients at institutions had a significantly higher mean DMFT than other settings There were statistically significant associations between decayed teeth and moderate and high intake of sweet drinks and frequency of dental visits Higher odds of filled teeth were associated with age, no oral hygiene assistance and high carer-contact
Pregliasco et al. (2001) (Italy)	Cross-sectional study	To evaluate the oral health status and treatment needs of a sample of adults with ID in order to improve service provision	219 adults with ID (male $n = 179$, female $n = 40$) living in a long-term-care institution with a mean age of 61.3 years	<ul style="list-style-type: none"> The degree of cooperation with dental examination was evaluated as good for 131 subjects (59.8%), fair for 79 (36.1%), and poor for nine (4.1%)

(Continued)

Table 1. Continued.

Authors, year (country)	Design and analysis	Objective	Population	Key findings
Rodriguez Vazquez, Garcillan, Rioboo, and Bratos (2002) (Spain)	Cross-sectional study	To analyse the prevalence of dental caries and the possible influence of extra-oral factors in a group of adults with IDD	A total of 166 adults with ID (male $n = 85$, female $n = 81$) ranging in age from 20 to 40 years with a mean age of 28.3 years	<ul style="list-style-type: none"> The percentage of residents who were edentulous was 21.5%, of whom 28 subjects (59.6%) were without dentures Evaluation showed an overall <i>DMFT</i> of 23.1 and the average number of missing teeth was 20.5 All subjects had periodontal disease The mean <i>DMFT</i> index for the whole sample was 5.97 Subjects in the oldest age group had the highest <i>DMFT</i> index and the lowest filled component There were no significant differences in the <i>DMFT</i> index and its components between the subjects who received a weekly fluoride mouth rinse ($n = 117$) and those who did not ($n = 49$) There was a significantly lower <i>DMFT</i> index ($p < .05$) in people with Down syndrome
^b Trihandini, Wiradidjaja Adiwoso, Erri Astoeti, and Marks (2013) (Indonesia)	Cross-sectional study	To describe and evaluate the oral treatment needs of Special Olympics athletes in Indonesia between 2004 and 2009	1217 athletes with ID (males $n = 776$, females $n = 441$) with a mean age of 13.46 years	<ul style="list-style-type: none"> More than 70% of athletes had visible untreated decay and 29.8% had gingival inflammation Pain in the oral cavity was reported by 28.6% Athletes who had untreated decay reported 6.67 times (95% CI OR; 4.00–11.14) more pain compared to those who did not have untreated decay 21.63% of the screened athletes were referred to the dentist for urgent treatment
^b Turner, Sweeney, Kennedy, and Macpherson (2008) (UK)	Cross-sectional study	Describe the oral health status of athletes with ID participating at the 7th UK Special Olympics in 2005	1033 athletes with ID (males $n = 672$, females $n = 361$) with a mean age of 28 years (range 8–73)	<ul style="list-style-type: none"> Older athletes were more likely to have fewer than 21 teeth and to have fillings, untreated decay, gum inflammation and heavy plaque levels Only 28% of athletes had 21 or more teeth, no fillings and no obvious decay 5% of participants were judged to require urgent treatment and 40% to require non-urgent treatment
Yuki, Fumiko, and Mitsugi (2015) (Japan)	Cross-sectional study	To identify and determine the prevalence of periodontopathic pathogens in adults with ID	145 outpatients with ID (males $n = 106$, females $n = 39$) with an age range 6–30 years	<ul style="list-style-type: none"> <i>S. mutans</i> and <i>S. sobrinus</i> were possessed by 78.7 and 83.5% of participants respectively The mean decayed filled teeth index (DFT) score of subjects positive for both <i>S. mutans</i> and <i>S. sobrinus</i> at after 1 year was significantly higher than that of those positive for <i>S. mutans</i> alone ($p < .01$) The increase in caries increment was also significantly greater in subjects with both bacteria detected ($p < .001$)
Zizzi et al. (2014) (Italy)	Cross-sectional study	To determine the influence of the place of living on periodontal status of people with Down syndrome and ID	62 people with DS and ID (male $n = 30$, female $n = 52$) with an age range of 9–37 years	<ul style="list-style-type: none"> No significant differences resulted between place of living when compared for gender, age and degree of ID Participants living in an institution and aged between 14 and 22 years had higher levels of plaque index, probing depth, clinical attachment loss and a lower number of surviving teeth compared to participants living at home Older age, greater BMI and greater degrees of ID were found to be significant predictors of periodontal conditions

^aAlthough this article did not state that the participants had ID, all in the study group had cerebral palsy and performed significantly poorer on intelligence tests than the control group without CP and some assumption has been made that this cohort had so degree of ID.

^bScreening studies from Special Olympics participants as part of the Special Smiles Program.

characteristics, and found the severity of anxiety increased with higher degrees of ID. In addition, the prevalence of dental anxiety was higher among females, and there was a significant correlation with age, where younger individuals had higher levels of dental anxiety. It was hypothesised that the higher prevalence of dental anxiety could be attributed to the lower psychological resources and lack of cognitive abilities such as memory, problem solving and planning that are experienced by this population.

Three studies required the collection and culturing of bacterial samples (Horie et al., 2014; Naka et al., 2009; Yuki et al., 2015) and these were all Japanese studies. These studies showed that people with ID have a higher concentration of bacteria that cause periodontal disease (Naka et al., 2009) as well as dental decay (Yuki et al., 2015). Horie's study (2014) found that there is no direct correlation between the infection with oral opportunistic pathogens (OOPs) and ID, though further studies suggest that the prevalence of some certain periodontopathic bacteria is slightly higher among people with ID (Naka et al., 2009; Yuki et al., 2015).

Seven studies – incorporating participants from India, Korea, USA, Ireland and Brazil – utilised a research design that included a comparison group (Ahuja et al., 2016; Chang et al., 2014; Chi et al., 2011; Chi et al., 2010; Dourado et al., 2013; Mac Giolla Phadraig et al., 2015; Oliveira et al., 2013). Participants with ID across these seven studies had significantly poorer oral health, more missing teeth, greater numbers of tooth extraction, more caries, fewer filled teeth, greater gingival inflammation, greater rates of endentulism (and of these, fewer used dentures) and had less preventative dentistry and poorer access to services when compared to their non-disabled comparison group. In addition, there was a link noted between insufficient oral care practices and increased caries risk plus greater executive function and lower caries risk. This pattern of poor oral health was consistent across all other studies with a number of noted variables that predicted poorer oral health. These include, but are not limited to, greater degrees of ID, living in an institution, being older, poor oral health behaviours, greater BMI, lack of compliance with oral hygiene routines, independence with daily oral hygiene practices, co-morbidity, co-occurring disabilities and problems accessing dental services.

Discussion

This study has provided a valuable insight into the oral health of people with ID. The majority of studies identified were from developed countries, which is consistent with the general literature on ID. Due to lacks in

legislation, infrastructure and expertise in identifying and supporting people with ID, there is generally a lack of epidemiological studies in developing countries (Mercadante, Evans-Lacko, & Paula, 2009; Njenga, 2009). The included studies where gender was reported, the total number of males with ID was greater than the total number of females which again is consistent with the gendered disparity in the prevalence of ID reported elsewhere in the literature (e.g., Wilson, Parmenter, Stancliffe, Shuttleworth, & Parker, 2010).

The review clearly shows that this population has significantly poorer oral health than non-disabled people with dental issues ranging from dental decay, gingiva inflammation to more severe periodontal disease. This is concerning as poor oral health has a negative impact on quality of life (Zucoloto et al., 2016) which can exacerbate pre-existing health disparities in people with ID. Compounding this is the fact that poor oral health has been linked to numerous systemic conditions like diabetes, respiratory disease and cardiovascular disease (Aida et al., 2011; Genco et al., 2001; Joshipura et al., 2003; Jung et al., 2011; Walls & Steele, 2001). It is important to highlight that the high prevalence of poor oral health is also evident in other marginalised at risk groups. For example, people with mental health are 2.7 times more likely to lose all their teeth compared to general population (Kisely, 2016). In addition, oral health problems are among the most prevalent health issues associated with people with drug addiction (Shekarchizadeh, Khami, Mohebbi, Ekhtiari, & Virtanen, 2013). Factors that contribute to poor oral health in these marginalised populations include medication induced dry mouth, increased alcohol and caffeine consumption and illicit substance use (COAG Health Council, 2015).

Similar to other marginalised groups, this review highlighted that limited access to dental services can also contribute to poor oral health among people with ID. This is an issue for the general population as well mainly due to the high cost of dental treatment in private practice and long waiting period to access public dental services in countries where such services are offered. To address this, it is important that policy makers include oral health support strategies in any schemes that are developed for people with ID. A perfect example is the National Disability Insurance Scheme (NDIS) that is being rolled out in Australia (Australian Department of Human Services, 2017). This scheme provides personalised support plans and budgets to create a more individualised set of service and supports. Incorporating oral healthcare supports into such a scheme, for example, training in oral care practice from either a speech pathologist, an ID nurse or an occupational therapist, and

supports for dental anxiety from behaviour support teams would greatly assist people with ID to avoid unnecessary oral health problems. However, as it stands, dental services in Australia remain funded by health budgets or are paid for by individuals and are not part of the NDIS framework.

The review has also identified numerous factors unique to people with IDD that can contribute to poor oral health. One factor is dental anxiety especially among younger people with ID, female patients with ID and those with greater degrees of ID. Dental anxiety and phobia are common among the general population as well with reports that up to approximately 19% of the population has high degrees of dental fear (Armfield, 2010). However, for people with ID the perceptions of dental pain and ability communicate discomfort may be more intense due to their cognitive impairment. Further, there is a known relationship between difficult behaviour and anxiety in people with ID (Pruijssers, van Meijel, Maaskant, Nijssen, & van Achterberg, 2014). In these instances, it would be important to have an appropriate dental anxiety scale designed specifically for people with ID. This would allow early identification of patients at risk and help determine the effectiveness of interventions such as the cognitive behaviour intervention reported by Prangnell and Green (2008) that showed promise in reducing dental anxiety. However, the Italian study reviewed (Fallea et al., 2016) used an old generic anxiety scale (1978) which was found to be hard to administer for people with ID. The inability of many people with ID to use mainstream scales is well documented (e.g., Stancliffe, Wilson, Bigby, Balandin, & Craig, 2014) and it is thus important to utilise or develop an ID-specific anxiety scale to increase dental treatment compliance.

Another factor that seems to contribute to poor oral health is living in an institution. This is worrying considering this is an environment that is supervised by health professionals such as nurses who are responsible in maintaining the health and wellbeing of the patient. It is possible that oral health care is not being actively promoted in these institutions due to various reasons such as limited oral health training among staff, lack of proper dental referral pathways, oral health not viewed as a priority, excessive workload and time constraints and understaffing. These reasons have been cited as contributing factors to the high prevalence of oral health problems among aged care people in residential facilities (Webb, Whittle, & Schwarz, 2013, 2015). Further research is needed to confirm current oral health practices among large residential settings for people with ID in order to develop appropriate strategies to support oral health care.

It is equally important to explore if the dental care system has adequately trained staff and resources to provide appropriate dental care for people with ID. It is possible that the dental care system may face similar issues to the healthcare system when dealing with people with ID such as problems with communication, under-prepared staff and unclear expectations of caregivers (Lewis, Gaffney, & Wilson, 2016). Examples of training strategies might include continuing professional development programs that provide oral health professionals with key information about the physical, mental and behavioural challenges of managing people with ID and effective ways of providing oral care to them in the dental setting. These programs could be offered through online modules or face to face workshops and should be made mandatory for all dentists involved in supportive programs for people with ID.

Limitations

There are several limitations to this review, the main one being the exclusion of articles that did not clearly identify the disability status of participants. For example, some excluded studies referred only to participants with “special needs”; this is too vague to be useful in a review article. Further, some studies referred generically to “developmental disability” yet also did not provide a descriptive breakdown of this definition. This is important as a person can have a developmental disability (e.g., cerebral palsy) but does not necessarily have ID. Several screening studies were conducted as part of the Special Olympics program and participants in these studies are unlikely to be representative of all people with ID as participation in the special Olympics is likely to be limited to those who can access and afford to go to the event and those who are able to participate in one of the events. In addition, that we excluded articles not written in English and those published prior to 2000 are other limitations. Finally, we did not include any grey literature, book chapters or books in this review and nor did we include any commentaries or case reports. Notwithstanding these limitations, to our knowledge this is the first scoping review of the published research literature that reports on the wide range of oral health status or problems and contributing factors among people with ID.

Conclusion

This study has confirmed that people with ID have significantly worse oral health problems compared to the general population. These problems can negatively impact the quality of life and pose additional health

and wellbeing challenges. Various factors have been identified that contribute to poor oral health for people with ID, some of which are unique to this population. Further research is required to identify appropriate interventions that can improve the oral health of people with ID and address the contributing factors.

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