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Abstract

Background: There have been several past reports that adults with intellectual disabilities experience poor oral health (tooth loss, periodontal health, untreated dental caries). Loss of a functional dentition has serious consequences, including problems with chewing, swallowing, nutrition, speech, temporomandibular joint osteoarthritis and pain, and systemic health conditions. Poor oral health is largely preventable through proactive oral care support. In recent years social care provision for adults has changed, with deinstitutionalisation and home-based personalised care now being the typical provision in high income countries. Hence, oral health inequalities might be reducing. However, there is limited recent evidence-synthesis on the topic. We aimed to address this.

Method: PROSPERO registration number: CRD42018089880. We conducted a PRISMA systematic review of publications since 2008. Four databases were searched with a clear search strategy, strict inclusion criteria for selection of papers, double scoring (two raters), systematic data extraction, and quality appraisal of included papers.

Results: 33/3,958 retrieved articles were included, of which 14 were drawn from dental service users and 10 from Special Olympic athletes, therefore not necessarily being representative of the wider population with intellectual disabilities. Despite this limitation, adults with intellectual disabilities were still shown to experience poor oral health. High levels of poor oral hygiene and gingivitis were found, with many also affected by periodontitis and untreated dental decay. There is clear unmet need relating to both periodontal (gum) and tooth health, leading to tooth loss.

Conclusions: Despite reports in the past of poor oral health among adults with intellectual disabilities, and despite it being preventable, there remains a high burden of poor oral health. This highlights the need to raise awareness, and for policies on effective daily oral care, and appropriate service provision. The importance of oral health and its possible negative sequelae needs to be elevated amongst carers and professionals.

Keywords

Intellectual Disabilities, Oral Health, Special Needs Dentistry, Systematic Review

Background

There have been many past reports of poor oral health in people with intellectual disabilities, but it is less clear whether, or the extent to which, these reflect current health and care. This is important, since poor oral health is largely preventable through proactive supportive oral care, including tooth brushing and regular dental checks (Faculty of Dental Surgery, 2012). Indeed, whilst people with intellectual disabilities experience many health inequalities compared with the general population, inequalities in oral health may be the inequality most likely to reduce with improvements/personalisation in care and support. In recent decades, there has been a major shift in care provision for people with intellectual disabilities in most high income countries, with deinstitutionalisation, and a move to more home-based person-centred support. In Scotland, for example, new policy introduced in 2000 required the closure of the long-stay intellectual disabilities hospitals and a programme of deinstitutionalisation, with the main care provision becoming supported-living in the community (The Scottish Executive, 2000). Following closure of the long-stay hospitals, there is some suggestion that health and social care provision has been continually improving for adults with intellectual disabilities (NHS Health Scotland, 2017). It is therefore possible that the extent of oral health inequalities experienced may have reduced in recent years.

A systematic review of publications up to 2008, found that adults with intellectual disabilities experienced poorer oral health compared to the general population, higher levels of edentulousness (tooth loss), worse periodontal (gum) health, and higher rates of untreated dental caries (decay)/low rates of restorative care compared to the general population (Anders & Davis, 2010). These findings, however, may reflect the outcomes of care and practices from some years previously, given the gestational period for oral and dental problems. While there has been a recent systematic review on the oral health status of children and adolescents with intellectual disabilities (Zhou et al. 2017)

reporting poorer oral health compared to the general population, little has been reported on adults with intellectual disabilities. A more up-to-date evaluation of the current oral health of people with intellectual disabilities would therefore provide a better indication of the extent of health inequalities/closure in the oral health inequalities gap since care provision has changed, or the need for further/more intensive dental public health input and support.

Oral health is not simply healthy teeth; it is the state of being free from pain and disease, and the presence of a functional dentition, facilitating chewing, swallowing, clear speech, nutrition, and normal digestion. Oral health is fundamental to general health and wellbeing, and this is particularly true for people with intellectual disabilities (de Knecht, Lobbezoo, Schuengel, Evenhuis, & Scherder, 2016; Oliveira et al., 2013; Persson, Axtelius, Söderfeldt, & Ostman, 2009). People with intellectual disabilities experience poor health in general, often with multimorbidity and complex additional care needs (Cooper et al., 2017; Hughes-McCormack et al., 2017; Kinnear et al., 2018). Furthermore, there is increasing evidence that poor oral health (namely periodontal disease) is associated with cardiovascular disease, coronary heart disease, diabetes mellitus, respiratory disease, and obesity (Bahekar, Singh, Saha, Molnar, & Arora, 2007; Hobbins, Chapple, Sapey, & Stockley, 2017; Kudiyirickal & Pappachan, 2015; Nibali et al., 2007; Spahr et al., 2006; U.S Department of Health and Human Services, 2000; Virtanen et al., 2017). This suggests that not only are adults with intellectual disabilities experiencing more oral health problems, but that they may present with more serious systemic consequences of these diseases compared to the general population (NHS Health Scotland, 2017; U.S Department of Health and Human Services, 2000).

Even amongst the older literature on evidence regarding oral health in intellectual disabilities, much is small-scale includes or is focused exclusively on children and adolescents, and is biased based on the heterogeneity of disabilities included in a sample, or the sampling source (Tiller, Wilson & Gallagher, 2001). This highlights the importance of a systematic review that includes quality appraisal of evidence. Consequently, we aimed to critically review the recent evidence base on oral health of adults with intellectual disabilities, focusing on the period since 2008, and restricted to articles involving adults living in community settings and not institutions. The specific research questions were:

- Do adults with intellectual disabilities still experience poor oral health, and to what extent?
- How is oral health most commonly measured in recent intellectual disabilities literature?

Methods

Data sources and search strategy

First we checked whether any planned/ in progress systematic reviews/meta-analyses were already registered. As none were, we then prospectively registered the review with the International Prospective Register of Systematic Reviews (PROSPERO, registration number CRD42018089880). The review was completed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist, flow diagram and guidelines (Shamseer et al., 2015), and initially began in February 2018 with the most recent search updated on the 2nd July 2018. We used a wide range of search terms for both oral health and intellectual disabilities, to identify the maximum number of articles (Fig. 1). We searched multiple electronic databases, specifically: PubMed Medical Literature Analysis and Retrieval System online (MEDLINE), Web of Knowledge/ Science (WoK/ WoS), Psychological Information Databases (PsycINFO), and Excerpta Medica dataBase (EMBASE). The reference lists of all relevant studies were also searched for any additional publications.

[Insert Figure 1 here]

Study screening and selection

Titles and abstracts were read by the first reviewer (LW) and screened using the inclusion and exclusion criteria. A random 10% of these articles were read by a second reviewer (LHM) to check for inconsistencies ensuring a systematic approach to article inclusion. Any discrepancies were intended to be resolved through discussion, and to inform ongoing selection of papers. The full text of potentially eligible studies was retrieved and assessed by eligibility and quality. The search was limited to articles published between 2008 and 2018 to provide a follow-up of the previous review (Anders & Davis, 2010). Strict inclusion and exclusion criteria were used to select articles:

Inclusion criteria

- Participants included adults (aged 18+) with intellectual disabilities living in community settings
- At least one quantitative outcome measure of oral health status
- Observational study design
- Studies from peer reviewed journals
- English language
- Published in or after 2008

Exclusion criteria

- Data for adults (aged 18+) with intellectual disabilities were not separately reported, or less than 50% of the sample were adults (aged 18+) with intellectual disabilities
- >50% of sample lived in institutional settings
- Case series of <20
- Grey literature

Data Extraction and Quality Assessment

Data extraction was completed using a pre-prepared database. Where it was unclear as to the type of disability or the age of the sample, authors were contacted requesting clarification. Quality assessment was independently undertaken using the Oxford Critical Appraisal Skills Programme (CASP) Checklist (Critical Appraisal Skills Programme, 2013). Each article was scored 0 or 1 for the 12 questions, resulting in a quality assessment CASP 'score' (Dunn, Hughes-McCormack, & Cooper, 2018). This assessment included the risk of bias with points deducted from articles sampling from single dental clinics, inaccurately measuring/ reporting intellectual disabilities, inappropriate statistics, small effect sizes with large confidence intervals/ increased chance of Type 1 Error and/ or lack of consideration of confounding factors. The second reviewer checked the CASP appraisal of 10% of the included papers, with the intention to resolve any discrepancies through discussion.

Results

Eleven study authors were contacted for additional information, of whom four replied. The initial search generated 3,958 articles, with 3,455 articles remaining after duplicates were removed. A second reviewer independently assessed a random selection of 10% of the titles and abstracts identified for full text review (n=3,455). Kappa statistics were used to assess the level of agreement between the two reviewers, which indicated almost perfect agreement (Cohen's k : 0.88). Once the final papers were selected for inclusion, and quality appraisals of these were made, the second reviewer assessed a random selection of 10% of these studies (n=33) for quality. Disagreements at both stages were resolved by consensus until 100% agreement was reached. The flow chart (Fig. 2) details the papers included/ excluded at each stage of identification, screening, eligibility, and inclusion. The number of publications selected for inclusion was 33 (Table 1), with the quality assessment revealing 17 articles to be of strong quality (score of ≥ 8).

[Insert Figure 2 here]

[Insert Table 1 here]

The descriptive summary of the papers published since 2008 (Table 1) indicates the different countries, sampling source, methodologies and outcome measures involved. There was a total of 14,160 adults with intellectual disabilities across the 33 studies, 30 of which were individual studies and 3 of which combined results from Special Olympics surveys. Most were cross-sectional convenience samples: 14 were drawn from users of dental service (and therefore not likely to be representative of the wider population with intellectual disabilities), 9 reported results of surveys conducted as part of the Special Olympics – Special Smiles (SO-SS) programs in various parts of the world, with 1 other reporting a combination of Special Olympic athletes and service users (these 10 studies therefore are also unlikely to be representative of the wider population with intellectual disabilities), and 7 were drawn from users of intellectual disabilities services. Of the remaining 2 studies, one used large-scale record-linkage methodologies (Morgan et al, 2012), and one was a cross-sectional cohort study (n=440: Davies et al, 2008).

Regarding the measures used, the 14 papers that recruited dental service users all reported findings from oral examinations (some additionally with radiographs), and the 9 special Olympics papers also reported from oral examinations. The combined Special Olympics/service user paper reported questionnaire data only. Of the 7 papers that reported on intellectual disabilities users, 4 reported from oral examinations, whilst 3 relied upon questionnaires only. The data-linkage study included linkage with oral health data, and the cohort study included oral examinations.

Most articles that included a clinical oral exam reported poor oral hygiene, signs of poor gingival health (including periodontitis), and a relatively high prevalence of decayed teeth in adults with intellectual disabilities.

Poor gingival health, with inflammation and bleeding of the gums, was frequently reported in adults with intellectual disabilities and this relates to the level of plaque control. Many of these studies involved dental service users (Alves et al., 2016; Batista, Moreira, Rauen, Corso, & Fiates, 2009; Finkelman, Stark, Tao, & Morgan, 2014; Ozgul et al., 2014; Seirawan, Schneiderman, Greene, & Mulligan, 2008; Zizzi et al., 2014) and in 4 papers a high prevalence of daily toothbrushing was reported (Fernandez, Descamps, Fabjanska, Kaschke, & Marks, 2016; Hsieh, Murthy, Heller, Rimmer, & Yen, 2018; Margaritis, Koletsi-Kounari, Mamai-Homata, & Kiriakou, 2012; Seirawan et al., 2008). Of the clinical studies assessing the more severe form of periodontal health (periodontitis), a significant level of disease was recorded, with the prevalence in adults with intellectual disabilities ranging from 22.5% - 69.2% (Alves et al., 2016; Cheng, Leung, & Corbet, 2008; Davies et al., 2008; Finkelman et al., 2014; Margaritis et al., 2012; Martinez-Martinez et al., 2013; Moosani et al., 2014; Morgan et al., 2012; Ozgul et al., 2014; Zizzi et al., 2014).

In addition to unmet needs relating to plaque control and periodontal health, our findings show that a similar problem exists in relation to untreated dental decay, with a high prevalence of decayed teeth

being reported in many studies (Dellavia, Allievi, Pallavera, Rosati, & Sforza, 2009; Fernandez, Declerck, Dedecker, & Marks, 2015; C. Fernandez et al., 2016; Fernandez et al., 2012; Finkelman et al., 2014; Hanke-Herrero, López Del Valle, Sánchez, Waldman, & Perlman, 2013; Hughes & Gazmararian, 2015; Leroy & Declerck, 2013; Morgan et al., 2012; Seirawan et al., 2008). The Decayed, Missing, Filled Teeth (DMFT) index measures past and present disease experience of teeth and, in addition to presence of decay, also assesses the number of teeth filled or extracted from the mouth (missing). The latter can be due to either dental caries or periodontal disease. Many studies provided a mean DMFT score for adults with intellectual disabilities and a range of values was recorded. The heterogeneity of the samples, particularly in relation to age, precludes meaningful quantitative synthesis of the DMFT data. However, the missing component of the index was relatively high in many cases. Regarding other clinical assessments of oral health, poor oral hygiene was measured by the use of the plaque index, gingival index, presence of calculus and toothbrushing frequency (Alves et al., 2016; Cheng et al., 2008; Leroy & Declerck, 2013; Margaritis et al., 2012; Ozgul et al., 2014; Schulte, Freyer, & Bissar, 2013; Seirawan et al., 2008; Zizzi et al., 2014). Periodontal health was measured mostly adhering to the World Health Organization standards, including the Community Periodontal Index (CPI) (World Health Organization, 2013) (Alves et al., 2016; Leroy & Declerck, 2013; Margaritis et al., 2012), and 2 studies as well as the SO-SS studies conducted visual soft tissue oral examinations (Davies et al., 2008; Knoll, Janal, & Khocht, 2008).

Poor quality of life associated with oral disease was reported in 2 studies (Alves et al., 2016; Couto, Pereira, Nunes, & Mendes, 2018). In studies which included adults in either a community-based or institution setting, poorer oral health was reported for the adults with intellectual disabilities living in an institution (Ozgul et al., 2014; Schulte et al., 2013; Zizzi et al., 2014). Two studies investigated the effects of periodontal treatment (Cheng et al., 2008; Tanaka et al., 2015) and both showed positive health outcomes.

Information collected as part of the SO – SS program tends to be relatively consistent, and the 6 surveys included in the review were held in the countries/ regions of: Italy, Belgium, Europe, USA, South America, and UK (Dellavia et al., 2009; Fernandez et al., 2016; Fernandez, Kaschke, Perlman, Koehler, & Marks, 2015; Fernandez et al., 2012; Hanke-Herrero et al., 2013; Turner, Sweeney, Kennedy, & Macpherson, 2008). The reported prevalence of decayed, missing and filled teeth are shown in Fig. 3. Additionally, all SO-SS surveys reported that some participants were experiencing oral pain and many were in need of urgent dental care, with prevalence of the latter being as high as 50% in the study from Italy (Dellavia et al., 2009).

In summary, to answer the two research questions, it appears that adults with intellectual disabilities still experience poor oral health, and a high level of unmet need is apparent. The majority of studies included a clinical oral examination.

[Insert Figure 3 here]

Discussion

Our findings show that adults with intellectual disabilities still experience poor oral health despite a previous review highlighting this, and the subsequent passage of time, with changing social care environments. The majority of selected papers used a clinical oral examination to assess oral health, rather than relying on interviews. These included use of: DMFT, plaque and gingival indices; calculus scores; the CPI; and visual soft tissue oral examinations.

The literature reviewed in the main was of low quality due to non-generalisability, for example, studies focussing only on the Special Olympics cohort, or dental clinic attendees. It was not possible to conduct a meta-analysis due to the heterogeneity of the studies for these reasons, and also the outcomes used, age ranges reported, and/or other population characteristics. Whilst accepting this limitation, the most striking result from this review was the pervasive finding of poor gingival health in adults with

intellectual disabilities, regardless of the population characteristics (inclusion/ exclusion of Down syndrome or autism or varying age groups). Almost all papers reported poor oral hygiene/ plaque control and the associated presence of gingivitis. However, regarding the more severe oral health disease of periodontitis, one of the most robust articles, with evidence from n= 4218 adults with intellectual disabilities, reported a high degree of periodontitis in every age group: 56% of adults aged 20-40 had periodontitis, which increased to 92.6% for those over the age of 60 (Morgan et al., 2012). For comparison, general USA adult population data estimates mild periodontitis to be prevalent in 13% of 30-34 year olds, and 53% for those over the age of 65 (Eke, Dye, Wei, Thornton-Evans, & Genco, 2012). The Global Burden of Disease study estimated that 10.8% of the world adult population has severe periodontitis (Marcenes et al., 2013), and although many articles did not classify the severity of the disease, current results indicate adults with intellectual disability continue to demonstrate a high burden of this oral disease.

Periodontitis is associated with bone loss and can lead to missing teeth, and may be more prevalent in adults with Down syndrome as well as intellectual disabilities (Khocht, Janal, & Turner, 2010). Additionally, there is a wealth of research in the general population demonstrating periodontitis to be associated with cardiovascular disease, coronary heart disease, diabetes mellitus, respiratory diseases and obesity (Bahekar et al., 2007; Cullinan, Ford, & Seymour, 2009; Hobbins et al., 2017; Holmstrup et al., 2017; Khader, Dauod, El-Qaderi, Alkafajei, & Batayha, 2006; Kudiyirickal & Pappachan, 2015; Meurman, Sanz, & Janket, 2004; Montebugnoli et al., 2004; Nibali et al., 2007; Spahr et al., 2006; Virtanen et al., 2017; Yu, Chasman, Buring, Rose, & Ridker, 2015). Therefore, as well as periodontitis presenting an oral health burden for adults with intellectual disabilities, it is also related to other systemic diseases which have an elevated prevalence in adults with intellectual disabilities (diabetes, respiratory disease, obesity and multimorbidity) (Cooper et al., 2015). The Longitudinal Health and Intellectual Disability Study of America included n= 1381 adults with intellectual disabilities, and reported gum disease to be an independent risk factor for cardiovascular disease, with 19.5% having

both gum disease and cardiovascular disease (Hsieh et al., 2018). This interrelationship between oral and systemic disease may create greater oral health inequalities for adults with intellectual disabilities.

Previous literature has indicated a high prevalence of dental caries in this group, and the results of this review also found a high level of untreated decay being reported in many studies. Many of the included studies indicated unmet need involved dental service users, and a large USA cohort reported a 69% prevalence of periodontitis despite dental attendance (Finkelman et al., 2014). The prevalence of fillings and tooth extractions is indicative of the service-user sampling source used, but for most articles, the regularity and reason for attendance (i.e. emergency or routine care) is unclear. The findings of unmet dental needs among adults with intellectual disabilities has important implications in relation to dental service systems, knowledge and skills training, and resources of primary care dental practitioners, be they public dental service or independent.

Many measures of oral health have known age-related effects, yet there is little research on the effects of age and oral health in adults with intellectual disabilities. This review included five papers whose sample included adults from across the life span, and three papers focusing specifically on older adults. Morgan and colleagues provided evidence that edentulism, caries experience, and poor gingival health all increase with age, and number of teeth decreases (Morgan et al., 2012). These results are similar to the worsening oral health that occurs in the general population with ageing. However, there is evidence suggesting adults with intellectual disabilities experience higher rates of edentulism compared to the general population, despite attending a dentist (Davies et al., 2008; Mac Giolla Phadraig et al., 2014). Other such results echo this: despite attending dental services (Couto et al., 2018; Cumella et al., 2000; Finkelman et al., 2014; Hall, Marshman, & Owens, 2011; Mac Giolla Phadraig et al., 2014; Seirawan et al., 2008), or reportedly having adequate oral hygiene (Dellavia et al., 2009; Hsieh et al., 2018; Margaritis et al., 2012), adults with intellectual disabilities continue to suffer poor oral health. Interestingly, whilst a Brazilian study (Alves et al., 2016) reported a 73% need for prosthodontics to replace missing teeth, the Irish Intellectual Disability Supplement to The Irish Longitudinal Study on

Ageing (IDS-TILDA) study showed that although there may be a high normative need for dental prosthetics (69%), there is a very low expressed need (4%) (Mac Giolla Phadraig et al., 2018). Additionally, few adults with intellectual disabilities wear their prescribed dentures (Davies et al., 2008; Mac Giolla Phadraig et al., 2018). These findings highlight the importance of the differences in proxy and self-reporting, a crucial consideration in this patient population (Mac Giolla Phadraig et al., 2018).

Oral health influences psychological health, wellbeing and life satisfaction (Christensen, Hede, & Nielsen, 2012; Gil-Montoya, Ferreira de Mello, Barrios, Gonzalez-Moles, & Bravo, 2015; Kisely, 2016; Locker, Clarke, & Payne, 2000; Masood, Newton, Bakri, Khalid, & Masood, 2017; Persson et al., 2009). Two papers reported an association between quality of life measures and oral health status, with the need for dental treatment and prostheses, presence of periodontal pockets and fewer number of teeth all having a negative impact on quality of life (Alves et al., 2016; Couto et al., 2018).

This review included 33 articles from an array of countries including Brazil, Belgium, Canada, China, Germany, Greece, Ireland, Italy, Japan, Mexico, Portugal, South Africa, South America, Turkey, UK, and the USA. The accompanying variation in geographic, dental and social policies makes comparisons of studies challenging, notwithstanding the various terminology used for adults with intellectual disabilities. While many of the articles reviewed were low in quality, our aim was to simply reflect the information provided in the literature regarding the heterogeneity of articles sampled and the selection criteria used. For example, whilst some articles included patients with Down syndrome and autism, others specifically excluded these groups. Additionally, some samples were based on service users and Special Olympics participants, and only a small number of studies used a more non-biased representative sample of adults with intellectual disabilities (Mac Giolla Phadraig et al., 2014; Morgan et al., 2012). There was also a great deal of variation in the mean age groups of samples included. A further caveat requiring discussion is the lack of inclusion of confounding factors amongst articles. There are a multitude of variables that influence oral health: from simple physical ability to complete oral hygiene (Gallagher & Scambler, 2012), malocclusion (Cabrita, Bizarra, & Graça, 2017) or dental

trauma from epileptic seizures (Aragon & Burneo, 2007) to the more complex influence of medication (Ciancio, 2004) or systemic diseases. People taking 5+ medications (polypharmacy) are at an increased risk of poor oral health due to anticholinergic burden causing xerostomia (dry mouth) leading to an increased risk of dental caries (Scottish Government Model of Care Polypharmacy Working Group, 2015; Vázquez, Garcillan, Rioboo, & Bratos, 2002). The implications of polypharmacy is of particular concern given the recognised problem within this group (Doan, Lennox, Taylor-Gomez, & Ware, 2013; Ghosh, Arulrajan, & Baldwin, 2010; Peklar et al., 2017). However, only 19 of the 33 articles included some consideration of the various confounds. A limitation of the review is that only 10% of the titles and abstracts were read by more than one person. Grey literature was also not included as part of the review as the authors agreed to include only peer-reviewed articles. However, this is also acknowledged as a possible limitation. Strengths of this review include its prospective registration, and robust adherence to the PRISMA checklist, including searching multiple databases, clear inclusion/exclusion criteria, , and systematic quality appraisal.

Another review has just been published on the oral health of people with intellectual disabilities but was not prospectively registered, and was published after we had selected studies for our data extraction (Wilson, Lin, Villarosa, & George, 2018). It scores low on the Assessing the Methodological Quality of Systematic Reviews (AMSTAR) checklist as no quality assessment was completed (Smith, Devane, Begley, & Clarke, 2011). Wilson et al., (2018) selected 36 papers for inclusion out of the 998 articles identified, and unlike us, included children as well as adults, institutionalised as well as community populations, did not require the studies to quantify oral health, and covered a time period twice as long as ours. Despite their broader remit, our review identified a significantly greater number of articles from a variety of countries (3958) of which we selected 33 for inclusion using our stricter inclusion/ exclusion criteria, 20 of which were not included in Wilson et al., (2018). The two reviews therefore are quite different and provide complimentary data and discussion.

Conclusions

This systematic literature review shows the continuing high prevalence of oral disease and treatment need among adults with intellectual disabilities, despite changes in care provision. However, most existing research is limited, and heterogeneous, and more research is needed on generalisable populations to quantify the extent of poor oral health. More research is required also to address the numerous confounding factors that undoubtedly influence oral health in this population group. The findings of this work and others show the need for individual countries to address the oral health inequalities faced by adults with intellectual disabilities. For example, in the UK when a person with intellectual disabilities turns 18 and moves into adulthood, their oral health fast deteriorates (Waldron et al., 2017). Dental caries has been a priority disease for public dental health for decades, but now people with intellectual disabilities are living longer, it is crucial to focus on this age-related oral health problem and not only focus on interventions aimed at children. Additionally, the importance of good oral hygiene and the possible sequelae associated with oral disease needs a higher profile and level of awareness than currently exists amongst care givers and professionals for adults with intellectual disabilities.

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