# Review of the dental treatment backlog of people with disabilities in Europe (\*)

Inès Phlypo<sup>1</sup>, Lynn Janssens<sup>1</sup>, Ellen Palmers<sup>2</sup>, Dominique Declerck<sup>2</sup>, Luc Marks<sup>3</sup>

- <sup>1</sup> Department of Oral Health Sciences, Special Needs in Dentistry, Ghent University, Ghent, Belgium
- <sup>2</sup> Department of Oral Health Sciences, Population Studies in Oral Health, KU Leuven, Leuven, Belgium
- <sup>3</sup> Center Special Care in Dentistry, Ghent University Hospital, Ghent, Belgium

## Corresponding author: ines.phlypo@ugent.be

(\*)Conference paper.
IDEALS Congress 23-25
August 2018 Amsterdam

The authors declare that they have no conflict of interest.

#### **KEYWORDS**

Disability
Oral health
Review
Determinants

J Forensic Odontostomatol 2019. Dec;(37): 3-42:49 ISSN :2219-6749

#### **ABSTRACT**

**Aim:** The present research aims at reviewing the oral health conditions and treatment needs of people with disabilities in Europe.

**Methods:** A comprehensive literature search was conducted using Medline and Embase with a timeframe from January 2008 until December 2017. Subsequently, a citation tracking was undertaken. Articles in English, French and Dutch were included.

**Results:** Forty-two articles were included. A variety of oral health problems and treatment needs was reported. More untreated carious lesions, less restorations, a higher number of extractions and less prosthetic rehabilitations were seen in people with disabilities compared with other individuals without disabilities. The oral hygiene level and the periodontal conditions were poor. Moreover, a higher risk of dental trauma, orthodontic problems and tooth wear were reported.

**Discussion:** Different determinants contribute to the oral health condition and treatment needs of people with disabilities. These determinants can be inherent in persons with a disability (biological factors), their lifestyle, the environment or the organization of oral health care. A treatment backlog was a common finding in people with disabilities. However, results need to be interpreted with caution because of the variety of people with disabilities included in this literature review. Proposed solutions can be put at the level of daily oral care, through oral health promotion programs and the creation of a supportive environment, but also at the level of dental attendance, facilitating the access to oral health care services and focusing the training of dental students and dentists.

**Conclusion:** This comprehensive review clearly shows a dental treatment backlog in people with disabilities. Solutions require efforts from the caregivers and dental professionals.

#### INTRODUCTION

Oral health is an integral part of the global health and is essential to the people's wellbeing.<sup>1-3</sup> In order to develop strategies and interventions to improve oral health in the Flemish part of Belgium, the Flemish Government made an agreement with the Flemish dentist associations and the Ghent University and KU Leuven departments of oral health sciences. The aim of this agreement was to develop preventive strategies, for the Flemish population in general on one hand, and for different groups of vulnerable individuals on the other.

In Flanders, oral health promotion strategies are currently being developed targeting people with low socioeconomic status, frail older persons and people with disabilities. The current review focuses on the latter. In 2012 about 15 percent of the world population had a disability, compared to a similar 16 percent of the Belgian 15-64 population.<sup>4,5</sup>

In order to align Flemish preventive oral health strategies with the actual oral health needs of people with disabilities, an overview of reported oral health problems and treatment needs was prepared. The current study aims at reviewing the oral health condition and treatment needs of people with disabilities in Europe.

#### **MATERIALS AND METHODS**

#### Definition of people with disabilities

In analogy with a previous national pilot study that took place in Belgium in 2014, people with disabilities were defined as "people who cannot take care of their own (oral) health because of a mental, physical or medical condition, irrespective of age".6 The current review focuses on children and adults with an intellectual or physical disability and people with autism. Since we intended to include only studies about people depending on others for their oral health, we excluded studies about people with a psychological, visual and/or hearing impairment without intellectual disability or studies including hospitalized people.

#### **Search Strategy**

A comprehensive literature search was conducted using Medline and Embase. The search queries for both databases are attached as appendix. Since only the recent situation was considered relevant, a timeframe for publication date was set from January 2008 until December 2017.

Subsequently, a selection of relevant papers based on title and abstract, and finally full-text, was undertaken. Only studies performed in Europe and published in English, French or Dutch were included to obtain information as close as possible to the situation in Flanders. Furthermore, a citation tracking via Google Scholar and the consulting of the reference lists of included articles was carried out to obtain a search as broad as possible.

#### RESULTS

The literature search resulted in 2735 publications in Medline and 965 publications in Embase. After the selection process, 42 studies were included. Children with myotonic dystrophy type I and children with disabilities had a higher DMFT (decayed, missing, and filled teeth) than children without disabilities.<sup>7,8</sup> However, in females with Rett syndrome and adults with Prader Willi syndrome, DMFT was lower than in the general population.9,10 In adolescents with ADHD (Attention-Deficit/Hyperactivity Disorder) and children with disabilities more teeth decay resulted untreated8,11, while less untreated tooth decay was detected in people with Down syndrome. 12-14 Children with Cerebral Palsy underwent more tooth extractions compared with children in general.<sup>15</sup> Moreover, children, adolescents and adults with a disability showed less dental restorations than the population in general.<sup>8,9,11,15-17</sup>

A higher plaque index was reported in both children and adults with disabilities.<sup>7,17,18</sup> Furthermore, in several groups, except for adults with an autism spectrum disorder, gingival health was worse in people with disabilities.<sup>9-11,19</sup> Studies reported signs of gingivitis in 39 to 70 percent of athletes with intellectual disabilities.<sup>12,20-26</sup> Moreover, in these athletes, signs of gingivitis were significantly correlated with age.<sup>22,25,26</sup>

Compared to the general population, edentulism was seen more often in people with intellectual disabilities. However, prosthetic rehabilitation was found less often 27-29, with a prevalence of edentulous people without prosthetic rehabilitation ranging from 18 to 61 percent in people with an intellectual disability. 6,25-27,30

A history of dental trauma was more frequent in several groups of children with disabilities.<sup>31,32</sup> Moreover, in children with disabilities the consequences of dental trauma remained untreated more often than in children without disabilities.<sup>33</sup> A higher prevalence of tooth wear related to bruxism was noted in children with Down syndrome and females with Rett syndrome.<sup>9,13</sup>

When considering orthodontic characteristics, severe orofacial morphological problems were seen more often in children and adolescents with disabilities.<sup>33</sup> Several subgroups of people with disabilities had a larger number of individuals with an anterior open bite.<sup>9,17,34</sup> In addition, adults with Prader Willi syndrome and children with Down

syndrome suffered from hypodontia more often. 10,35

#### **DISCUSSION**

The aim of this review was to describe the oral health condition and treatment needs of people with disabilities in Europe. Common findings were a higher frequency of diseases, diseases at a more severe stage and a dental treatment backlog in both children and adults with disabilities.

#### **Explanatory Factors**

Many determinants contribute to the oral health and treatment needs. According to the model proposed by Lalonde (1974), they can be categorized in biological factors, lifestyle, environment and the organization of the oral health care services.<sup>36</sup>

#### **Biological Factors**

The biological factors are characteristics of a person, which are hard to control or change.<sup>36</sup> Cognitive factors influence oral hygiene habits of people with intellectual disabilities (e.g. they do not know why and how to brush their teeth, they forget tooth brushing).<sup>37</sup> Moreover, physical factors, like a lack of coordination, sensory problems or abnormal craniofacial and oral muscle tone, seem to make tooth brushing more challenging.<sup>37</sup> Furthermore, oral health maintenance could be perceived not as a priority issue, because other medical or social issues are considered more important.<sup>37,38</sup>

Antipsychotic, anticonvulsant and anxiolytic medication are known to trigger side effects (e.g. xerostomia, gastroesophageal reflux disease, tongue oedema, tongue spasms, bruxism or gingival hyperplasia).<sup>39,40</sup> Moreover, xerostomia and gastroesophageal reflux disease increase the risk of tooth decay, periodontal diseases and erosion of the tooth surfaces.<sup>39</sup> In addition, gastrointestinal problems influence oral health. Idaira et al. (2008) detected significantly more carious lesions in people with disabilities who ruminate.<sup>41</sup> In people fed by tube, less carious lesions but more calculus were described.<sup>41,42</sup>

#### Lifestyle

Lifestyle factors can be influenced more easily than biological factors. In children with Down syndrome, compared to children without Down syndrome, no differences in food habits were described by Areias et al. (2011).<sup>13</sup> Significantly

less food moments were reported in adults with autism spectrum disorders, children with disabilities and adolescents with disabilities.<sup>19,43</sup> Furthermore, Hennequin et al. (2008) described a lower consumption of sugar drinks in children and adolescents with disabilities.<sup>33</sup>

Considering tooth brushing, 74 to 96 percent of athletes with an intellectual disability reported to brush their teeth at least once a day.<sup>12,21-23,25</sup> However, compared to the population in general, less tooth brushing moments were seen in adults with autism spectrum disorders, children with disabilities and adults with disabilities.<sup>19,43</sup>

#### **Environment**

Parents and caregivers are most often the oral care providers to people with disabilities. However, Klingberg and Hallberg (2012) described that, in the context of the oral cavity, parents tended to focus more on communication and feeding problems than on tooth decay and periodontal problems. They also felt unsure about delivering oral care to their child with a disability.<sup>38</sup>

Similarly, Chadwick et al. (2018) described that caregivers felt uncertain when carrying out oral care (e.g. when gums bleed).<sup>37</sup> Moreover, they could face uncooperative behaviours, like hitting or biting <sup>37,44,45</sup>, which might create barriers to provide oral care. These barriers partly explain why, despite the necessity of help and assistance in tooth brushing, help to people with disabilities is not always provided when needed.<sup>20,46-48</sup>

#### Organization of oral health care services

The final explanatory factor lies in the management of oral health care services. In addition to daily oral care, dental visits contribute to obtain and maintain oral health. However, people with disabilities face barriers to visit the dentist (**Table 1**). The other way round, barriers and concerns about dental treatment of people with disabilities are also mentioned by dentists (**Table 2**).

In the Greek study of Gizani et al. (2014), more than 90 percent of the dentists mentioned that dental treatment of people with disabilities was difficult but rewarding.<sup>49</sup> Nevertheless, Marks et al. (2012) described that 86 percent of the Flemish and Dutch dentists had emotional concerns when they treated people with disabilities.<sup>50</sup>

Treatment options in people with disabilities can be limited, which has been demonstrated in literature. Children, adolescents and adults with a disability receive less dental restorations than the population in general.<sup>8,9,II,I5-I7,5I,52</sup> Dziwak et al. (2017) reported less use of dental sealants in German children with disabilities.<sup>8</sup>

**Table 1.** Barriers to professional dental care mentioned by people with disabilities

Accessibility and architecture<sup>29,64,75,76</sup>

Costs of treatment and/or lack of reimbursement<sup>75-77</sup>

Distance and difficulties with transport<sup>72,75</sup>

Fear<sup>29,76,78</sup>

Little availability dentists<sup>29,64,72,75,76</sup>

Long waiting list<sup>64,72,75</sup>

Missing the appointment<sup>19</sup>

No perceived need (e.g. no pain)<sup>76</sup>

Physical disability or non-cooperation<sup>76,79</sup>

Uncertain treatment is possible<sup>75</sup>

**Table 2.** Barriers to professional dental care mentioned by dentists

Accessibility and equipment44,49,73
Concerns about durability of treatment <sup>73</sup>
Concerns about medical history <sup>73</sup>
Extra staff needed <sup>73</sup>
Extra time needed80
Lack of communication <sup>38,44,49,73</sup>
Lack of experience <sup>38</sup>
Lack of financial support44,49,73
Lack of knowledge and training <sup>38,44,49</sup>
Lack of treatment options44,73
Non-cooperation33,38,44,46,80

Importantly, Bissar et al. (2010) showed a lower DMFT in young German athletes with an intellectual disability when they had at least one

dental sealant.<sup>20</sup> In Belgium, less dental radiographs, less orthodontic evaluation and treatments, and less endodontic treatments were registered in people with disabilities. Consequently, more emergency treatments were seen in both children and adults with disabilities compared to the general population.<sup>51,52</sup>

#### Limitations

The current results need to be interpreted with caution. Due to a broad definition of people with disabilities, a variety of disabilities and impairments were included in this literature review. Furthermore, the studied populations were mostly small and did not represent all age groups. Moreover, since a variety of measuring tools was used, comparison of the results from different studies was challenging.

Despite these limitations, this review illustrates the dental treatment needs and treatment backlog of people with disabilities in Europe. In addition, the findings are confirmed in literature from outside Europe.<sup>53-61</sup>

#### PROPOSED SOLUTIONS

#### Daily oral care

To improve the oral health of people with disabilities, both the daily oral care and the professional dental care should be ameliorated. Oral health promotion interventions, targeting people with disabilities, their family and caregivers, are indispensable to improve daily oral care. Furthermore, a supportive environment is essential to convert acquired knowledge and skills into good practices and attitudes.37,53-56,58,62-65 Oral hygiene should be individualized by the adaptation of materials (e.g. choice of toothbrush or toothpaste) and tooth brushing should be incorporated in the daily routine of the person with a disability.37,66,67 A customized use of fluoride can help to achieve and maintain the desired oral health level.

#### **Dental visit**

Dentists should be encouraged to treat people with disabilities. Therefore, (general) dentists should be trained to make them feel more comfortable in treating people with disabilities. Both undergraduate and specialized postgraduate courses are necessary, including education on the following issues: impact of disabilities on oral

health; barriers for people with disabilities (for daily and professional oral and dental care); clinical decision making and treatment options; communication with people with disabilities. 49,50,68-73 General dentists should be able to treat people with mild to moderate intellectual disabilities, whereas specialist care should be reserved to more severe cases.

Dentists should receive more financial support when treating people with disabilities and they should be encouraged to make their offices more accessible to disabled people. Finally, a network of dentists should be established, including referral pathways from primary to specialist care. The network should be based on a foundation of general dentists 70.72, and people with disabilities should be informed about this network and how it works.

#### Ethical dilemma?

The described treatment backlog in people with disabilities can clearly be considered unethical. There is a need for solutions and people with disabilities need support and assistance in maintaining their oral health. However, providing this support and assistance might cross the borders of respecting the patient's autonomy. After all, the possibility of making choices should not be denied to people with disabilities.74

Therefore, one should strive for a balance between the theoretically known needs and those perceived by people with disabilities. People with disabilities can be guided in making healthy choices, for example by creating a supportive environment. Moreover, people with disabilities can participate in the decision making process of implementing oral health strategies, which empowers their autonomy. Ultimately, this will align oral health interventions with their needs in order to make the interventions more durable and sustainable.

#### **CONCLUSION**

This comprehensive review clearly demonstrates a dental treatment backlog in people with disabilities. Efforts from caregivers and dental professionals are required, based on appropriate training and education.

#### **ACKNOWLEDGMENTS**

The authors would like to thank the partners of the Flemish Knowledge Centre Oral Health (the Flemish government, Ghent University, KU Leuven, Vlaamse Beroepsvereniging Tandheelkunde and Verbond der Vlaamse Tandartsen) for their support in the realization of this review. Furthermore, we express our gratitude to Dr. Jannick De Tobel for his critical review of the manuscript.

#### REFERENCES

- I. Watt RG. Strategies and approaches in oral disease prevention and health promotion. Bull World Health Organ. 2005;83(9):711-8.
- 2. Clarkson J, Watt RG, Rugg-Gunn AJ, Pitiphat W, Ettinger RL, Horowitz AM, et al. Proceedings: 9th World Congress on Preventive Dentistry (WCPD): "Community Participation and Global Alliances for Lifelong Oral Health for All," Phuket, Thailand, September 7-10, 2009. Adv Dent Res. 2010;22(1):2-30.
- 3. Petersen PE. The World Oral Health Report 2003: continuous improvement of oral health in the 21st century—the approach of the WHO Global Oral Health Programme. Community Dent Oral Epidemiol. 2003;31 Suppl 1:3-23.
- 4. Eurostat. Statistical Office of the European Communities. Eurostat: Regional Statistics 2015 [Available from: http://ec.europa.eu/eurostat/web/health/disability/data/database].
- 5. World Health Organization. WHO global disability action plan 2014-2021: Better health for all people with disability: World Health Organization; 2015.
- 6. RIZIV. Pilootproject Mondzorg voor Personen met Bijzondere Noden (PBN) Brussels: Rijksinstituut voor Ziekte-en Invaliditeitsverzekering; 2011 [Available from:

- http://www.specialdent.be/library/documents/201\_pilootproject-mondzorg-voor-personen-metbijzondere-noden-pbn-.pdf].
- Engvall M, Sjogreen L, Kjellberg H, Robertson A, Sundell S, Kiliaridis S. Oral health status in a group of children and adolescents with myotonic dystrophy type I over a 4-year period. Int J Paediatr Dent. 2009;19(6):412-22.
- 8. Dziwak M, Heinrich-Weltzien R, Limberger K, Ifland S, Gottstein I, Lehmann T, et al. Dental health and odontogenic infections among 6-to 16-year-old German students with special health care needs (SHCN). Clin Oral Investig. 2017;21(6):1997-2006.
- 9. Fuertes-Gonzalez MC, Silvestre FJ. Oral health in a group of patients with Rett syndrome in the regions of Valencia and Murcia (Spain): A case-control study. Med Oral Patol Oral Cir Bucal. 2014;19(6):e598-604.
- 10. Saeves R, Nordgarden H, Storhaug K, Sandvik L, Espelid I. Salivary flow rate and oral findings in Prader-Willi syndrome: a case-control study. Int J Paediatr Dent. 2012;22(1):27-36.
- II. Blomqvist M, Ahadi S, Fernell E, Ek U, Dahllof G. Dental caries in adolescents with attention deficit

- hyperactivity disorder: a population-based follow-up study. Eur J Oral Sci. 2011;119(5):381-5.
- 12. Dellavia C, Allievi C, Pallavera A, Rosati R, Sforza C. Oral health conditions in Italian Special Olympics athletes. Spec Care Dentist. 2009;29(2):69-74.
- 13. Areias CM, Sampaio-Maia B, Guimaraes H, Melo P, Andrade D. Caries in Portuguese children with Down syndrome. Clinics (São Paulo, Brazil). 2011;66(7):1183-6.
- 14. Macho V, Palha M, Macedo AP, Ribeiro O, Andrade C. Comparative study between dental caries prevalence of Down syndrome children and their siblings. Spec Care Dentist. 2013;33(1):2-7.
- 15. Grzic R, Bakarcic D, Prpic I, Jokic NI, Sasso A, Kovac Z, et al. Dental health and dental care in children with cerebral palsy. Coll Antropol. 2011;35(3):761-4.
- 16. Bakarcic D, Prpic I, Ivancic-Jokic N, Bilic I, Lajnert V, Bukovic D. Dental status as a quality control health care parameter for children with disabilities. Coll Antropol. 2009;33(1):139-42.
- 17. Orellana LM, Silvestre FJ, Martinez-Sanchis S, Martinez-Mihi V, Bautista D. Oral manifestations in a group of adults with autism spectrum disorder. Med Oral Patol Oral Cir Bucal. 2012;17(3):e415-9.
- 18. Khocht A, Janal M, Turner B. Periodontal health in Down syndrome: contributions of mental disability, personal, and professional dental care. Spec Care Dentist. 2010;30(3):118-23.
- Blomqvist M, Bejerot S, Dahllöf G. A cross-sectional study on oral health and dental care in intellectually able adults with autism spectrum disorder. BMC Oral Health. 2015;15(1):81.
- Bissar AR, Kaschke I, Schulte AG. Oral health in 12- to 17-yearold athletes participating in the German Special Olympics. Int J Paediatr Dent. 2010;20(6):451-7.
- 21. Fernandez Rojas C, Wichrowska-Rymarek K, Pavlic A, Vinereanu A, Fabjanska K, Kaschke I, et al. Oral health needs of athletes with intellectual disability in Eastern Europe: Poland, Romania and Slovenia. Int Dent J. 2016;66(2):113-9.
- Fernandez C, Declerck D, Dedecker M, Marks L. Treatment needs and impact of oral health screening of athletes with intellectual disability in Belgium. BMC Oral Health. 2015;15:170.
- 23. Fernandez C, Descamps I, Fabjanska K, Kaschke I, Marks L. Treatment needs and predictive capacity of explanatory variables of oral disease in young athletes with an intellectual disability in Europe and Eurasia. Eur J Paediatr Dent. 2016;17(1):9-16.
- 24. Marks L, Fernandez C, Kaschke I, Perlman S. Oral cleanliness and gingival health among Special Olympics athletes in Europe and Eurasia. Med Oral Patol Oral Cir Bucal. 2015;20(5):e591-7.
- 25. Leroy R, Declerck D, Marks L. The oral health status of special olympics athletes in Belgium. Community Dent Health. 2012;29(1):68-73.
- 26. Turner S, Sweeney M, Kennedy C, Macpherson L. The oral health of people with intellectual disability participating in the UK Special Olympics. J Intellect Disabil Res. 2008;52(Pt 1):29-36.
- 27. Mac Giolla Phadraig C, McCallion P, Cleary E, McGlinchey E, Burke E, McCarron M, et al. Total tooth loss and complete denture use in older adults with intellectual disabilities in Ireland. J Public Health Dent. 2015;75(2):101-8.

- 28. Schulte AG, Freyer K, Bissar A. Caries experience and treatment need in adults with intellectual disabilities in two German regions. Community Dent Health. 2013;30(1):39-44.
- 29. Owens J, Jones K, Marshman Z. The oral health of people with learning disabilities a user-friendly questionnaire survey. Community Dent Health. 2017;34(1):4-7.
- 30. Leroy R, Declerck D. Objective and subjective oral health care needs among adults with various disabilities. Clin Oral Investig. 2013;17(8):1869-78.
- 31. Gerreth K, Gerreth P. Occurrence of oral trauma in young epileptic patients. Eur J Paediatr Dent. 2014;15(1):13-6.
- 32. Bagattoni S, Sadotti A, D'Alessandro G, Piana G. Dental trauma in Italian children and adolescents with special health care needs. A cross-sectional retrospective study. Eur J Paediatr Dent. 2017;18(1):23-6.
- 33. Hennequin M, Moysan V, Jourdan D, Dorin M, Nicolas E. Inequalities in oral health for children with disabilities: a French national survey in special schools. PLoS One. 2008;3(6):e2564.
- 34. Cabrita JP, Bizarra MF, Graca SR. Prevalence of malocclusion in individuals with and without intellectual disability: A comparative study. Spec Care Dentist. 2017;37(4):181-6.
- 35. Andersson EM, Axelsson S, Katsaris KP. Malocclusion and the need for orthodontic treatment in 8-year-old children with Down syndrome: a cross-sectional population-based study. Spec Care Dentist. 2016;36(4):194-200.
- 36. Lalonde M. A New Perspective on the Health of Canadians: A Working Document. 1974.
- 37. Chadwick D, Chapman M, Davies G. Factors affecting access to daily oral and dental care among adults with intellectual disabilities. J Appl Res Intellect Disabil. 2018;31(3):379-94.
- 38. Klingberg G, Hallberg U. Oral health not a priority issue a grounded theory analysis of barriers for young patients with disabilities to receive oral health care on the same premise as others. Eur J Oral Sci. 2012;120(3):232-8.
- Cockburn N, Pradhan A, Taing MW, Kisely S, Ford PJ. Oral health impacts of medications used to treat mental illness. J Affect Disord. 2017;223:184-93.
- 40. Robbins MR. Dental management of special needs patients who have epilepsy. Dent Clin North Am. 2009;53(2):295-309, ix.
- 41. Idaira Y, Nomura Y, Tamaki Y, Katsumura S, Kodama S, Kurata K, et al. Factors affecting the oral condition of patients with severe motor and intellectual disabilities. Oral Dis. 2008;14(5):435-9.
- 42. Hidas A, Cohen J, Beeri M, Shapira J, Steinberg D, Moskovitz M. Salivary bacteria and oral health status in children with disabilities fed through gastrostomy. Int J Paediatr Dent. 2010;20(3):179-85.
- 43. Krekmanova L, Hakeberg M, Robertson A, Braathen G, Klingberg G. Perceived oral discomfort and pain in children and adolescents with intellectual or physical disabilities as reported by their legal guardians. Eur Arch Paediatr Dent. 2016;17(4):223-30.

- 44. de Jongh A, van Houtem C, van der Schoof M, Resida G, Broers D. Oral health status, treatment needs, and obstacles to dental care among noninstitutionalized children with severe mental disabilities in The Netherlands. Spec Care Dentist. 2008;28(3):111-5.
- 45. Risma KM, Weber-Gasparoni K, Swenson SE, Ettinger RL, Qian F. Group home caregivers' comfort levels regarding physical resistance during oral hygiene care. Spec Care Dentist. 2015;35(3):123-31.
- 46. Descamps I, Marks L. Oral health in children with Down syndrome: Parents' views on dental care in Flanders (Belgium). Eur J Paediatr Dent. 2015;16(2):143-8.
- 47. Mårtensson Å, Ekström AB, Engvall M, Sjögreen L. Oral hygiene aspects in a study of children and young adults with the congenital and childhood forms of myotonic dystrophy type 1. Clin Exp Dent Res. 2016;2(3):179-84.
- 48. Phadraig CMG, el-Helaali R, Burke E, McCallion P, McGlinchey E, McCarron M, et al. National levels of reported difficulty in tooth and denture cleaning among an ageing population with intellectual disabilities in Ireland. Journal of disability and oral health. 2014;15:2.
- 49. Gizani S, Kandilorou H, Kavvadia K, Tzoutzas J. Oral health care provided by Greek dentists to persons with physical and/or intellectual impairment. Spec Care Dentist. 2014;34(2):70-6.
- 50. Marks L, Adler N, Blom-Reukers H, Elhorst JH, Kraaijenhagen-Oostinga A, Vanobbergen J. Ethics on the dental treatment of patients with mental disability: results of a Netherlands - Belgium survey. J Forensic Odontostomatol. 2012;30 Suppl 1:21-8.
- 51. Leroy R, Declerck D. Oral health care utilization in children with disabilities. Clin Oral Investig. 2013;17(8):1855-61.
- 52. Leroy R, Declerck D. Oral health-care utilization in adults with disabilities in Belgium. Eur J Oral Sci. 2013;121(1):36-42.
- 53. Anders PL, Davis EL. Oral health of patients with intellectual disabilities: a systematic review. Spec Care Dentist. 2010;30(3):110-7.
- 54. Bartolomé-Villar B, Mourelle-Martínez MR, Diéguez-Pérez M, de Nova-García M-J. Incidence of oral health in paediatric patients with disabilities: Sensory disorders and autism spectrum disorder. Systematic review II. J Clin Exp Dent. 2016;8(3):e344.
- 55. Chau YCY, Peng SM, McGrath CPJ, Yiu CKY. Oral Health of Children With Attention Deficit Hyperactivity Disorder: Systematic Review and Meta-Analysis. J Atten Disord. 2017:1087054717743331.
- 56. da Silva SN, Gimenez T, Souza RC, Mello-Moura ACV, Raggio DP, Morimoto S, et al. Oral health status of children and young adults with autism spectrum disorders: systematic review and meta-analysis. Int J Paediatr Dent. 2017;27(5):388-98.
- Marks L, Wong A, Perlman S, Shellard A, Fernandez C. Global oral health status of athletes with intellectual disabilities. Clin Oral Investig. 2018;22(4):1681-8.
- Morgan JP, Minihan PM, Stark PC, Finkelman MD, Yantsides KE, Park A, et al. The oral health status of 4,732 adults with intellectual and developmental disabilities. J Am Dent Assoc. 2012;143(8):838-46.
- 59. Sabuncuoglu O, Irmak MY. The attention-deficit/hyperactivity disorder model for traumatic dental injuries: a

- critical review and update of the last 10 years. Dent Traumatol. 2017;33(2):71-6.
- Winter K, Baccaglini L, Tomar S. A review of malocclusion among individuals with mental and physical disabilities. Spec Care Dentist. 2008;28(1):19-26.
- 61. Zhou N, Wong HM, Wen YF, McGrath C. Oral health status of children and adolescents with intellectual disabilities: a systematic review and meta-analysis. Dev Med Child Neurol. 2017;59(10):1019-26.
- 62. Glassman P, Miller C. Dental disease prevention and people with special needs. J Calif Dent Assoc. 2003;31(2):149-60.
- 63. Mac Giolla Phadraig C, Nunn J, Dougall A, O'Neill E, McLoughlin J, Guerin S. What should dental services for people with disabilities be like? Results of an Irish Delphi panel survey. PLoS One. 2014;9(II):e113393.
- 64. Mac Giolla Phadraig C, Dougall A, Stapleton S, McGeown D, Nunn J, Guerin S. What should dental services for people with disabilities in Ireland be like? Agreed priorities from a focus group of people with learning disabilities. Br J Learn Disabil. 2016;44(4):259-68.
- 65. Rosenberg SS, Kumar S, Williams NJ. Attention deficit/ hyperactivity disorder medication and dental caries in children. J Dent Hyg. 2014;88(6):342-7.
- 66. Buda LV. Ensuring Maintenance of Oral Hygiene in Persons with Special Needs. Dent Clin North Am. 2016;60(3):593-604.
- 67. Glassman P, Anderson M, Jacobsen P, Schonfeld S, Weintraub J, White A, et al. Practical protocols for the prevention of dental disease in community settings for people with special needs: the protocols. Spec Care Dentist. 2003;23(5):160-4.
- 68. Coyle CF, Humphris GM, Freeman R. Dentists' training and willingness to treat adolescents with learning disabilities: the mediating role of social and clinical factors. Community Dent Health. 2013;30(4):263-8.
- 69. Dougall A, Thompson SA, Faulks D, Ting G, Nunn J. Guidance for the core content of a Curriculum in Special Care Dentistry at the undergraduate level. Eur J Dent Educ. 2014;18(1):39-43.
- 70. Faulks D, Freedman L, Thompson S, Sagheri D, Dougall A. The value of education in special care dentistry as a means of reducing inequalities in oral health. Eur J Dent Educ. 2012;16(4):195-201.
- 71. Phadraig CMG, Griffiths C, McCallion P, McCarron M, Nunn J. Communication-based behaviour support for adults with intellectual disabilities receiving dental care: A focus group study exploring dentists' decision-making and communication. J Intellect Disabil. 2017;1744629517738404.
- 72. Prabhu NT, Nunn JH, Evans D, Girdler N. Access to dental care—parents' and caregivers' views on dental treatment services for people with disabilities. Spec Care Dentist. 2010;30(2):35-45.
- 73. Smith G, Rooney Y, Nunn J. Provision of dental care for special care patients: the view of Irish dentists in the Republic of Ireland. J Ir Dent Assoc. 2010;56(2):80-4.
- Brands W, Naidoo S, Porter S, Sereny M, van Dijk W, Welie J. Dental Ethics Manual 2: FDI World Dental Federation; 2018.
- 75. Gerreth K, Borysewicz-Lewicka M. Access Barriers to Dental Health Care in Children with Disability. A Questionnaire Study of Parents. J Appl Res Intellect Disabil. 2016;29(2):139-45.

- 76. Mac Giolla Phadraig C, Burke E, McCallion P, McGlinchey E, Nunn J, McCarron M. Dental attendance among older adults with intellectual disabilities in Ireland. Spec Care Dentist. 2014;34(6):265-72.
- 77. Blaizot A, Hamel O, Folliguet M, Herve C, Meningaud JP, Trentesaux T. Could Ethical Tensions in Oral Healthcare Management Revealed by Adults with Intellectual Disabilities and Caregivers Explain Unmet Oral Health Needs? Participatory Research with Focus Groups. J Appl Res Intellect Disabil. 2017;30(1):172-87.

### APPENDIX

#### Medline (via PubMed - "all fields"):

("Autism" OR "Behavior disorder" OR "Cognitive dysfunction" OR "Cognitive dysfunction" [MeSH Terms] OR "Dental care for disabled" OR "Dental care for disabled" [MeSH Terms] OR "Disability" OR "Disabled person" OR "Disabled persons" [MeSH Terms] OR "Learning disorder" OR "Mental deficiency" OR "Mental infantilism" OR "Neurodevelopmental disorders" OR "Neurodevelopmental disorders" [MeSH Terms] OR "Thought disorder") AND ("Dental health behavior" OR "Dental health care" OR "Dental health education" OR "Dental health motivation" OR "Dental health promotion" OR "Dental health services" OR "Dental health services" [MeSH Terms] OR "Dental prevention" OR ("Health behavior" AND ("Dentistry" OR "Dental health")) OR (("Health behavior" OR "Health behavior" [MeSH Terms]) AND (("Dentistry" OR "Dentistry" [MeSH Terms]) OR ("Oral health" OR "Oral health" [MeSH Terms]))) OR ("Health promotion" AND ("Dentistry" OR "Dental health")) OR (("Health promotion" OR "Health promotion" [MeSH Terms]) AND (("Dentistry" OR "Dentistry" [MeSH Terms]) OR ("Oral health" OR "Oral health" [MeSH Terms]))) OR "Health education, dental" OR "Health education, dental" [MeSH Terms] OR "Oral health behavior" OR "Oral health care" OR "Oral health education" OR "Oral health motivation" OR "Oral health promotion" OR "Oral health services" OR "Mouth hygiene" OR ("Motivation" AND "Dentistry" OR "Dental health")) OR (("Motivation" OR "Motivation" [MeSH Terms]) AND (("Dentistry" OR "Dentistry" [MeSH Terms]) OR ("Oral health" OR "Oral health" [MeSH Terms]))) OR "Preventive dentistry" OR "Preventive dentistry" [MeSH Terms] OR "Public health dentistry" OR "Public health dentistry"[MeSH Terms] OR ("Public health service" AND ("Dentistry" OR "Dental health")) OR "Dental

- 78. Blomqvist M, Dahllof G, Bejerot S. Experiences of dental care and dental anxiety in adults with autism spectrum disorder. Autism Res Treat. 2014;2014:238764.
- 79. Mac Giolla Phadraig C, Nunn J, Carroll R, McCarron M, McCallion P. Why do edentulous adults with intellectual disabilities not wear dentures? Wave 2 of the IDS TILDA cohort study. J Prosthodont Res. 2017;61(1):61-6.
- 80. Baird WO, McGrother C, Abrams KR, Dugmore C, Jackson RJ. Access to dental services for people with a physical disability: a survey of general dental practitioners in Leicestershire, UK. Community Dent Health. 2008;25(4):248-52.

determinants" OR "Dental disease assessment" OR "Dental health" OR "Dental health literacy" OR "Dental health surveys" OR "Dental health surveys" [MeSH Terms] OR "Determinants, dental" OR "Determinants, oral" OR ("Epidemiology" AND ("Dentistry" OR "Dental health")) OR ("Epidemiology" OR "Epidemiology" [MeSH Terms]) AND (("Dentistry" OR "Dentistry" [MeSH Terms])) OR ("Oral health" OR "Oral health" [MeSH Terms]))) OR "Mouth disease" OR "Need for dental care" OR "Need for oral care" OR "Oral health determinants" OR "Oral health" OR "Oral health" [MeSH Terms] OR "Oral health" Iteracy" OR "Stomatognathic Diseases" OR "Stomatognathic Diseases" [MeSH Terms])

#### Embase ("all fields"):

(Autism' OR Behavior disorder' OR Disability' OR 'Disabled person' OR 'Learning disorder' OR 'Mental deficiency' OR 'Mental infantilism' OR 'Thought disorder') AND (Dental health behavior' OR Dental health care' OR 'Dental health education' OR 'Dental health motivation' OR 'Dental health promotion' OR 'Dental prevention' OR ('Health behavior' AND ('Dentistry' OR 'Dental health')) OR ('Health promotion' AND ('Dentistry' OR 'Dental health')) OR 'Oral health behavior' OR 'Oral health care' OR 'Oral health education' OR 'Oral health motivation' OR 'Oral health promotion' OR 'Oral health services' OR 'Mouth hygiene' OR ('Motivation' AND ('Dentistry' OR 'Dental health')) OR ('Public health service' AND ('Dentistry' OR 'Dental health')) OR 'Dental determinants' OR 'Dental disease assessment' OR 'Dental health' OR 'Dental health literacy' OR 'Determinants, dental' OR 'Determinants, oral' OR ('Epidemiology' AND ('Dentistry' OR 'Dental health')) OR 'Mouth disease' OR 'Need for dental care' OR 'Need for oral care' OR 'Oral health determinants' OR 'Oral health literacy')