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RESEARCH ARTICLE

DETERMINING THE BARRIERS TO ACCESS DENTAL SERVICES FOR PEOPLE WITH A DISABILITY: A QUALITATIVE STUDY

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ABSTRACT

AIM:

To determine the perceptions of carers of people with a disability in terms of the problems they face in accessing dental care.

METHOD:

The survey was based on the modified Penchansky's 5A classification. It focused on members of a local disability support agency and was completed as part of their ongoing quality improvement processes.

RESULT:

A total of 169 carers took part, with a quarter indicating that the person they cared for did not have a regular dentist. Nearly 25% of the participants found it extremely difficult to obtain appropriate oral health care. Amongst the participants 10% had to abandon dental treatment due to difficulties, while 13% have yet to receive any sort of dental care. Amongst school-aged children, 64.5% were unable to receive dental care from the school dental service.

CONCLUSION:

The study was conducted to obtain an insight and understanding of how people with a disability and their primary caregivers experience dental care. Several concerns were identified, with most related to the process of providing care (patient-professional interaction factors) and the structure of the dental health system and its operation (factors related to access, affordability and information systems.) Targeted strategies aimed at providing affordable and appropriate services to people with disabilities should be prioritised.

SO WHAT?

The study showed emerging concerns among the participants relating to providing information regarding dental care options, as well as concerns regarding the availability and accessibility of the services. Further research will be conducted using the standardized tool the Measure of Processes of Care, and findings will translate to help initiate a program with the help of Developmental Disability Western Australia to provide information.

KEYWORDS

disability, dental care, access, Australia.

INTRODUCTION

The World Health Organisation's (WHO) global disability action plan 2014–2021, defines disability as "an umbrella term for impairments, activity limitations and participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual (environmental and personal) factors" [1]. According to the WHO it is estimated that more than 1 billion people are living with any sort of disability, and this accounted for roughly 15% of the global population, or one in seven people [1]. In 2019 the Australian Institute of Health and Welfare (AIHW) reported that about 4.4 million people in Australia, or about 18% of the population, have a disability [2].

The population distribution of disability status is not even, with prevalence rates of disability higher in women, older people and people from lower socio-economic status [1,2]. Numerous studies have been conducted enumerating various barriers to accessing health care for people living with a disability [1-5]. These barriers include longer waiting times, affordability of the services, limited availability of the services, difficulty accessing facilities and buildings, discrimination by health professionals, lack of communication between different health services and insufficient skills and knowledge of health professionals [6]. Disability is recognized not only as a global public health issue, but also a basic human rights issue [1,4,5,7]. People living with a disability have equal rights to have good oral health and should enjoy equal access to health care and equal quality of health care [4, 5,7-9].

Previous studies showed that people with a disability have a higher risk of having dental caries and periodontal disease, coupled with poorer oral hygiene than people without disabilities [1,4,5,8,10-12]. A major portion of people living with a disability also depend on carers for their oral hygiene and dental visits [3,13]. The dental treatment of people with a disability is also more time consuming and requires additional emotional and physical involvement from health professionals along with their primary care givers [4, 14]. All these factors play a significant role in placing a burden on the total quality of life of the affected individual, his/her immediate family, and the community in which they live.

The disability sector in Western Australia (WA) consists of a combination of both government and non-government services. This can be confusing for families in navigating the system. Local area co-ordinator (LAC) services are there to support families however, and their primary function is to assist with the co-ordination of various services (Disability Services Commission WA 2003).

Against this background, a survey was carried out amongst members of a disability support agency in Western Australia, one of the States in Australia. The aim of this study was to obtain an insight and understanding of how people with a disability and their primary caregivers experience dental care and access to dental services.

MATERIALS AND METHODS

SURVEY DESIGN

The survey was designed by a small community reference group of local advocates working for Developmental Disability WA. The membership of the group included people with any disability and their families residing in Western Australia.

This survey (anonymous questionnaires) focused on members of a local disability support agency, and was completed as part of the agency's ongoing quality improvement processes. The opportunistic survey was completed in the middle of 2016 and was carried out to identify problems relating to dental service access. Secondary analysis of these questionnaires was then carried out.

DATA COLLECTION

The survey was conducted using Survey Monkey online services, with anonymous open-ended questions. The answers to the survey questions were in the form of yes and no options, with an open section for qualitative expression of their views. The participants were the primary care givers or family members reporting on behalf of the person living with a disability.

These anonymous questionnaires were then reviewed and deductively mapped to their related themes based on the modified Penchansky's definition of access [16,17]. According to Penchansky and Thomas, access reflects the fit between characteristics and expectations of the health providers and their clients. They grouped these characteristics into five as of access to care: affordability, availability, accessibility, accommodation, and acceptability. A sixth dimension, namely awareness, was

later added to a modified version of the framework 16,17]. A total of 8 questions in the survey were related to access. Ethics approval: Ethics approval was sought (and exemption provided) from the Human Ethics Committee at The University of Western Australia (RA/4/20/4088).

RESULTS

QUANTITATIVE STUDY

There were a total of 169 participants who were the primary carers or family members of a person with a disability, and among those, 24% did not have any regular dentist (Figure 1). Amongst the participants, 28% found it extremely difficult or nearly impossible to provide proper daily oral care for the person with a disability (Figure 2). The majority of the participants (79%) also reported as having difficulties in participation when receiving dental examinations or treatment (Figure 3). Participants who responded that it was "extremely difficult" to provide proper oral care for the person living with a disability, were 8 times more likely to respond that the person living with a disability had difficulties to participate in dental treatment or examination (Figure 3).

One in ten (9.7%) of the participants indicated that dental treatment of the person with a disability had to be abandoned due to difficulties, while 13% have yet to receive any sort of dental care (Figure 4). Among the participants who had school-aged children with any disability, the vast majority (64.5%) faced the problem of the school dental service being unable to provide their treatment (Figure 5).

FIGURE 1. PERSONS WITH A DISABILITY HAVING A REGULAR DENTIST.

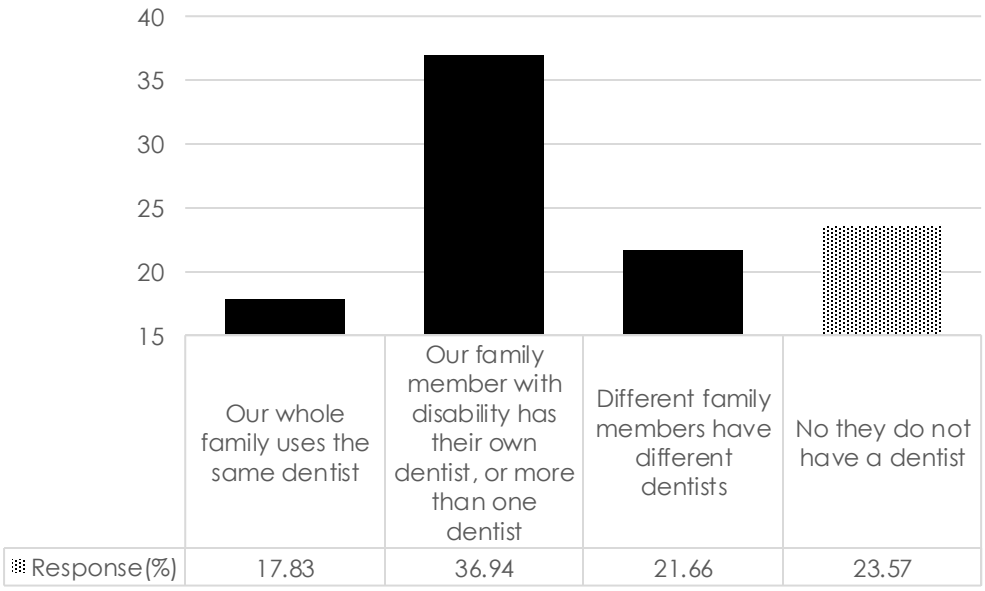


FIGURE 2. EASE OF TEETH CLEANING

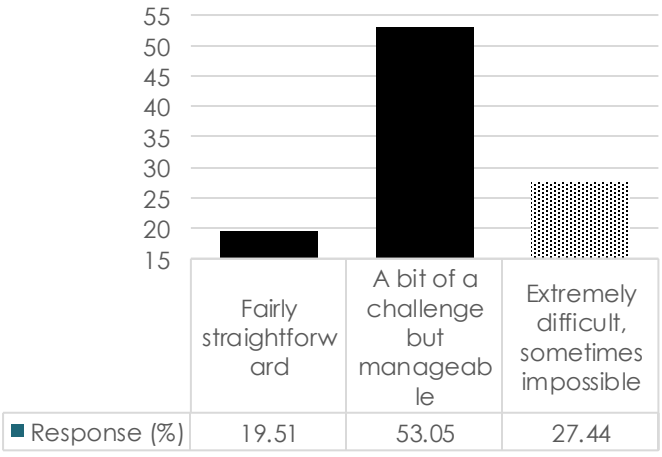


FIGURE 3. ABILITY AND CAPACITY OF PERSON WITH INTELLECTUAL DISABILITY TO PARTICIPATE IN DENTAL EXAMINATIONS AND TREATMENT

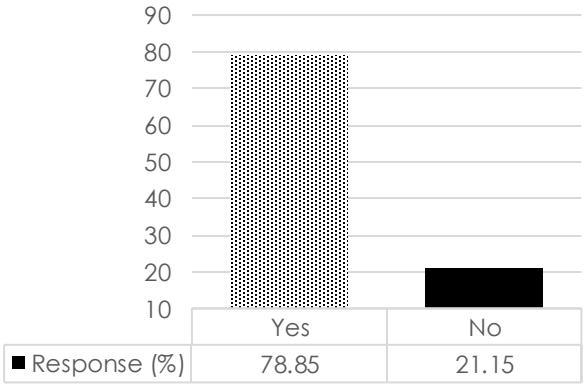


FIGURE: 4. ACCESS TO DENTAL TREATMENT.

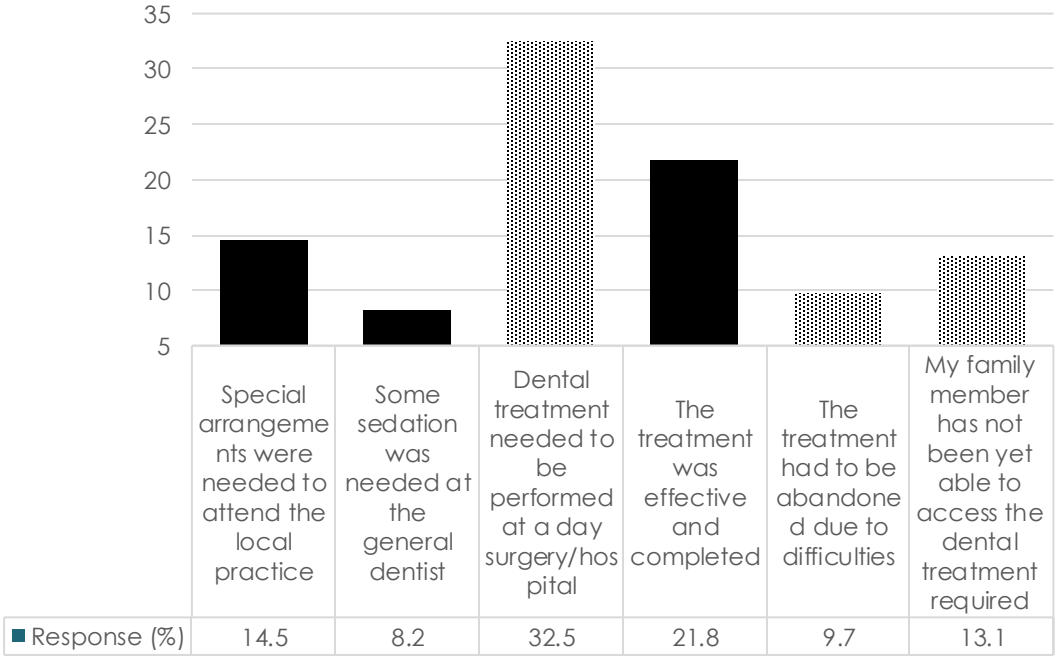
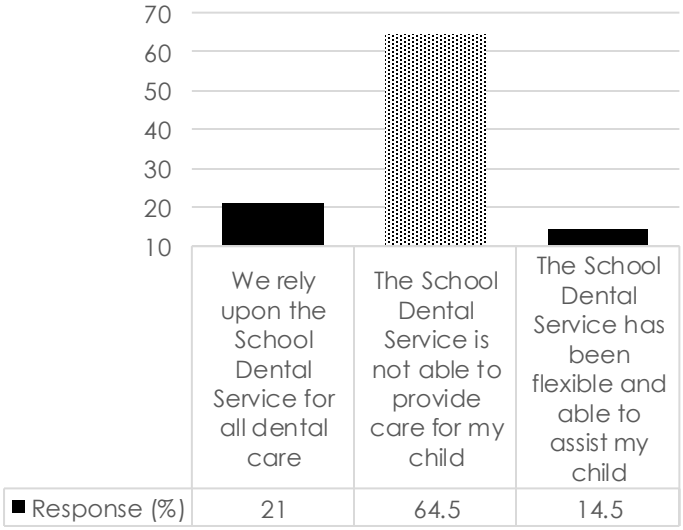


FIGURE 5. EXPERIENCE WITH SCHOOL DENTAL SERVICES



QUALITATIVE STUDY

Open-ended questions provided the opportunity for participants to share their views and experiences in terms of accessing dental care. Their perceptions were analysed and themed according to the five dimensions of the term "accessibility" [16,17] as proposed by Pechancsky:

AVAILABILITY

Availability measures the extent to which the provider has the requisite resources, such as personnel and technology, to meet the needs of the client. The participants reported lack of service, long waiting times, or refusal of dental care either due to inappropriate dental equipment or no dentist available to meet the special needs of people with a disability.

"Still waiting to hear from dental surgery about his treatment for surgery and braces but it's been 3yrs so I think it won't happen."

"My child (now 28) requires an anaesthetic every 3 - 5 years for dental treatment. If these treatments had been closer together, she would not have needed to have 9 extractions at the second to last operation. I do not like having to wait months for a simple check-up at dentist - a procedure that should be carried out regularly every 12-18 months without me reminding them, and I am very angry at being told there was a two year waiting list for treatment in 2013, a wait I managed to get down to one year after writing to members of parliament and others, although we still had to travel to Perth because she is supposedly an anaesthetic risk."

"The waiting list for my son to see an Orthodontist I have been told is about 2 years. What if this is too late? Some of his adult teeth are coming through as a double tooth with the adult tooth above the baby tooth. More needs to be done so the wait list isn't so long."

"He had tooth pain and was on a waiting list for six weeks until we could get him seen. During that time, I had to give him pain relief and because he was so distressed by the pain he pulled out 3 of his teeth one of them with the roots intact. Psychologically this was extremely difficult to have to see my child go through this not to mention the distress he was in."

"The negatives was the time it took to access emergency dental services the first time took six weeks the second time a month. I think this is way too long for a child to be in pain and almost caused me to have a nervous breakdown due to stress."

ACCESSIBILITY

Accessibility refers to geographic accessibility, which is determined by how easily the client can physically reach the provider's location. The participants did not visit a dentist because the service was too far or the service was not optimised structurally and functionally for them to access.

"It's all too far away school clinics should be for all school kids disabled or not why should we have to stressfully travel?"

"We travel a long way for my son to visit the private practice of the paediatric dentist he had previously as they have a good relationship, but this is not ideal, and not affordable."

"In general, the health system has been accommodating of the challenging behaviours etc. but a negative is travelling to city (a long distance for home) to have dental work done. Not been told clearly what happening on the day etc...."

"Attending general practise dentists is expensive and many of them don't cater for wheelchairs, due to restricted spaces, many being in older renovated homes."

AFFORDABILITY

Affordability is determined by how the provider's charges relate to the client's ability and willingness to pay for services The participants reported insufficient financial funds, extra out of pocket payments, and dental services being too expensive.

"I have 2 children with autism. Both of them need to be sedated in day hospital for basic treatment e.g. fillings, baby teeth removal. It was very expensive. Despite having private health insurance, I was out of pocket $2800.00. I am dismayed that private practice dentists don't recognise the health concession card and charge well above the rate that health insurers cover, hence why I was so much out of pocket."

"Very good service but user pay and expensive will exclude a lot of people on low income. Anything more detailed means seeing a specialist in Perth. 4.5 hours away. Careful

coordination must happen regarding X-rays need a cons first then treatment needs to be next day or means another trip, no subsidy huge addition of costs need accommodation and transport."

"Living in the country, on a low income and reliant on the public dental clinic means that there is little ability to meet the dental care needs for someone who requires anaesthetic for treatment unless we take a trip to Perth (at our own cost - not covered by Patient Assisted Transport) so it gets put in the too hard basket, with the hope that there is not a crisis requiring urgent dental treatment."

"We access the special needs dental centre, though it can be unreliable. I'm a student so struggle with the costs associated with dental care for my son to access private, though have the entry considered doing that instead."

ACCOMMODATION

Accommodation reflects the extent to which the provider's operation is organized in ways that meet the constraints and preferences of the client. Of greatest concern are hours of operation, how telephone communications are handled, and the client's ability to receive care without prior appointments. The participants reported negative experience with booking appointments and a poor referral system.

"All previously mentioned - HUGE Stress to go to Perth for dental work and especially as they will not book him for surgery over phone and make us go back and forth... cannot express the impact this has on our family and little son."

"And despite URGENT need, it took weeks to get a Princess Margaret Hospital dental appointment, made to drive 900km round trip for exam and back for surgery again.... HUGE impact for a super stressed little boy. He was in severe pain and could be again now whilst we wait again just for a check-up."

"We have only seen school dental once, we attend the special needs dental clinic in North Perth. Even then it's never regular enough and I always have to ring and follow up even though they say he will get a recall!"

"We were referred by school dental nurse as it was identified that my child had a need for a filling and my child would not sit for the work and would need sedation, it took couple of months before we could then see to the school dental dentist who then referred us to the special needs dentist for the same reason, it took a few more months to get into the special needs dentist who agreed my child would not sit for the work required and would require sedation, we were then referred to PMH, it took a few more months and then when we were seen by the dental nurse there they agreed again that my child would not sit for the work and would require sedation and there was a one year wait list however if the tooth got infected and formed an abscess I should come in for emergency. I then opted to go private to the paediatric dentist and had it sorted in 6 weeks, unfortunately it took us so long getting referred from service to service that my child had to have the tooth removed completely."

ACCEPTABILITY

Acceptability captures the extent to which the client is comfortable with the more immutable characteristics of the provider, and vice versa. These characteristics include the age, sex, social class, and ethnicity of the provider (and of the client), as well as the diagnosis and type of coverage of the client. The participants reported feelings of insecurity and discrimination at the dental service. Many also reported a negative attitude of the dentist or staff and their knowledge of how to handle people with a disability.

"Dentist experience as a toddler was horrific and extremely traumatising. Dentist rammed a piece of polypipe in his mouth and examined his teeth while he screamed (held him down)."

"When my son initially attended a paediatric dentist, despite them having a very good reputation, they did not accommodate for my son at all. Consultations were rushed, I was encouraged to restrain my son so that examinations could take place, and my son's anxieties increased."

"Some dentists are totally unaware of the needs of children with autism, and how enormously stressful they find the experience from a sensory perspective. Extreme patience and kindness is required!"

"I would never recommend this service, I explained the situation and asked for the first appointment they told me they understood ASD and yet they shoved a mirror in his mouth never explaining what they were going to do (this was his first dentist appointment) then a polisher my son became very anxious and they started telling him to be still

I tried to intervene but was told they know what they are doing, I couldn't get out of there quick enough."

"I tried using the School Dentist, but they had no understanding of ASD and refused any of my advice and made his first dental session extremely scary and had no idea the damage they had done, nor did they care. I am furious that the public dentist are so uncaring including admin staff."

AWARENESS

Awareness refers to a service that is aware of the local context and population need (and could then provide more appropriate and effective care), and patients could better access and use such services if they were simply aware of them in the first place. The participants had poor oral health awareness and little knowledge of the services available and their options.

"Are there any private dentists/oral surgeons who are prepared to treat people with high intellectual and physical needs? At this stage I see there is no advantage to my sister having private medical as she does not receive any benefit - cannot choose any practitioner, cannot receive immediate treatment. Sadly, even money can't buy her service/treatment."

"14-year-old son with intellectual disability finished primary school end of 2014; no more school dentists appointments have been made (I thought they were to be until end high school (?)) - So, he will commence seeing our family dentist in January 2016."

"We have never known that school has a dental service for special need kids."

"The fact is that my child is now out of the age range to access School Dental Services. Unsure of where to go for ongoing dental services."

"Princess Margaret Hospital have been great, but my son is now at the age he won't be able to access princess Margaret so need to know where to go."

"Regional Hospital does not seem to be geared to dental work at all-no facility to take x rays while under anaesthetic, very little time allocated to dentists. Dr Y used to be available but not last year. Dr X was fantastic. Where do we go next time?"

DISCUSSION

This study provides insight to the perspectives and experiences of the members of Developmental Disability WA in regard to dental care and barriers to access dental services.

Findings showed that many participants did not have a regular dentist, some have not received any dental care at all, and many commented that dentists were not aware of the needs of people with disabilities and did not have adequate experience to manage their care. Previous studies have shown the lack of trained special care dentists as a barrier to access of dental care for people with a disability [3-7], which also result in longer waiting times.

School dental services were also not able to provide appropriate services to children with disabilities. The results overall is an indication of problems with availability and accessibility of services, and other specific service-related issues, such as inadequate knowledge and experience of staff, and lack of infrastructure. Similar problems have been identified in a U.S study [20], and many studies have also shown that access to dental care and dental visits was generally better for people living in dedicated care institutions than those living independently or in family homes [3,5,18]. The participants in this study were mostly living independently or in family homes, thereby encompassing people at higher risk for experiencing unmet dental needs [3, 5, 18].

Similar problems with affordability and accessibility, including cost, travel distances, waiting times, wheelchair access, and disability parking have also been highlighted by previous studies [3-7, 22-23]. Patients in this study also reported feelings of discrimination, insecurity, anxiety and fear. A recent study from Canada [8] also reported the experience of discrimination and insecurity among wheelchair users, where many participants reported feeling insecure in a dental chair. It is also seen that some people with a disability are unwilling to seek dental care due to feelings of discrimination [8]. In 2019 the AIHW reported that about 42% of the reports lodged to Australian Human Rights Commission are about disability discrimination [2].

The Measure of Processes of Care (MPOC) is the instrument used to measure the success of a family-centred service [19], and it is used to measure the range to which the

provided services are family centred. It includes the following five domains: Enabling and partnership; providing specific information; providing general information; respectful and supportive care; and co-ordinated and comprehensive care. A previous survey [19] showed that the highest rated domain was 'respectful and supportive care' while 'providing general information' was rated as the worst. Many participants in the current survey also reported issues with the lack of an appropriate information system, especially around referral pathways. The reported lack of general information confirms findings of other studies using the MPOC, which showed that providing general information was rated the lowest in their study [19,21].

In Australia's National Oral Health Plan 2015-2024, "people with additional and/or special health care needs" is listed as one of the four priority populations in Australia that experience the most significant barriers to accessing oral health care and have the greatest burden of oral disease [24]. Overall, findings in this study support this, and identified both structure and process-related problems. In the public sector the structure-related problems, such as spatial access, lack of facilities, service availability, unclear information, affordability, referral pathways, resource shortages and waiting lists, can be improved at a health service/system level. Data collection on exactly where services are most needed, and at what level, is necessary, with ongoing monitoring. Targeted and sustainable strategies aimed at providing affordable or subsidised, appropriate services and interventions to people with disabilities should be prioritised.

Process-related problems mostly identified issues in terms of the patient-professional interaction, with comments on behaviour management skills and experience of dental health professionals, as well as shortages in special needs dentistry specialists. This indicates a need for improved training and competency of dentists in the management and treatment of patients with special needs, as well as building a specialist workforce capacity to meet the identified needs.

CONCLUSION

The study was conducted to obtain an insight and understanding of how people with a disability and their primary caregivers experience dental care. Several concerns were identified, with most related to the process of providing care (patient-professional interaction factors) and the structure of the dental health system and its operation (factors related to access, affordability and information systems.) Targeted strategies aimed at providing affordable and appropriate services to people with disabilities should be prioritised.

CONFLICTS OF INTEREST

None to declare

References

1. World Health Organization. WHO global disability action plan 2014-2021. Better health for all people with disability. ISBN 978 92 4 150961 9. Available at: https://www.who.int/publications/i/item/who-global-disability-action-plan-2014-2021
2. Australian Institute of Health and Welfare 2020. People with disability in Australia 2020. Canberra: AIHW. Available from: https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/people-with-disability/prevalence-of-disability
3. Pradhan A, Slade GD, Spencer AJ. Access to dental care among adults with physical and intellectual disabilities: residence factors. Australian Dental Journal. 2009 Sep;54(3):204-211.
4. Gerreth K, Borysewicz-Lewicka M. Access Barriers to Dental Health Care in Children with Disability. A Questionnaire Study of Parents. Journal of Applied Research in Intellectual Disabilities. 2015; 29. 10.1111/jar.12164.
5. Sermsuti-Anuwat N, Pongpanich S. Perspectives and experiences of Thai adults using wheelchairs regarding barriers of access to dental services: a mixed methods study. Patient Prefer Adherence. 2018;12:1461-1469.
6. da Rosa SV, Moysés SJ, Theis LC, Soares RC, Moysés ST, Werneck RI, Rocha JS. Barriers in Access to Dental Services Hindering the Treatment of People with Disabilities: A Systematic Review. International Journal of Dentistry. 2020; vol. 2020, ID 9074618, https://doi.org/10.1155/2020/9074618
7. McColl M, Forster D, Shortt S, Hunter D, Dorland J, Godwin M, et al. Physician Experiences Providing Primary Care to People with Disabilities. Healthcare Policy. 2008;4(1):e129-e47.
8. Rashid-Kandvani F, Nicolau B, Bedos C. Access to Dental Services for People Using a Wheelchair.

American Journal of Public Health. 2015;105(11):2312–2317.

9. Dougall A, Fiske, J. Access to special care dentistry, part 1. Access. British Dental Journal. 2008; 204. 605-16. 10.1038/sj.bdj.2008.457.
10. Anders PL, Davis EL. Oral health of patients with intellectual disabilities: A systematic review. Special Care Dentistry 2010; 30: 110–117. doi:10.1111/j.1754-4505.2010.00136.x
11. Kancherla V, Van Naarden Braun K, Yeargin-Allsopp M. Dental care among young adults with intellectual disability. Research in Developmental Disabilities. 2013; 34 1630–1641 http://doi.org/10.1016/j.ridd.2013.02.006
12. Owens PL, Kerker BD, Zigler E, Horwitz SM. Vision and oral health needs of individuals with intellectual disability. Mental Retardation and Developmental Disabilities Research Reviews. 2006;12(1):28-40. doi:10.1002/mrdd.20096
13. Cumella S, Ransford N, Lyons J, Burnham H. Needs for oral care among people with intellectual disability not in contact with community dental services. Journal of Intellect Disability Research. 2000; 44:45-52. DOI: 10.1046/j.1365-2788.2000.00252.x
14. Burtner AP, Jones JS, McNeal DR, Low DW. A survey of the availability of dental services to developmentally disabled persons residing in the community. Special Care in Dentistry. 1990;10, 182–184.
15. Disability Services Commission WA (2003) Review of the Local Area Coordination Program, Western Australia. Disability Services Commission, Perth, Australia. Available at: http://www.derby.gov.uk/media/derbycitycouncil/contentassets/documents/adultsocialcare/WesternAustraliaGorvernment-Review-of-Local-Area-Coordination.pdf Accessed January 2017
16. Penchansky R, Thomas JW. The concept of access: definition and relationship to consumer satisfaction. Medical Care. 1981 Feb;19(2):127-40.
17. Saurman E. Improving access: modifying Penchansky and Thomas's Theory of Access. Journal of Health Services Research Policy. 2016;21(1):36-39. doi:10.1177/1355819615600001
18. Horner-Johnson W, Dobbertin K, Beilstein-Wedel E. Disparities in dental care associated with disability and race and ethnicity. Journal of the American Dental Association. 2015;146(6):366–374.
19. Dyke, P, Buttigieg P, Blackmore A, Ghose A. Use of the Measure of Processes of Care for families (MPOC-56) and service providers (MPOC-SP) to evaluate family-centred services in a paediatric disability setting. Child Care Health Development. 2006; 32, 167–176. doi:10.1111/j.1365-2214.2006.00604.x
20. Mofidi M, Rozier RG, King RS. Problems With Access to Dental Care for Medicaid-Insured Children: What Caregivers Think. American Journal of Public Health. 2002 ;92(1):53-8.
21. Raghavendra P, Murchland S, Bentley M, Wake-Dyster W, Lyons T. Parents' and service providers' perceptions of family-centred practice in a community-based, paediatric disability service in Australia. Child Care Health Development. 2007; 33: 586–592. doi:10.1111/j.1365-2214.2007.00763.x
22. Rocha LL, de Lima Saintrain VM, Pimentel Gomes Fernandes Vieira-Meyer A. Access to dental public services by disabled persons. BMC Oral Health. 2015;15:35.
23. Rouleau T, Harrington A, Brennan M, et al. Receipt of dental care and barriers encountered by persons with disabilities. Special Care Dentistry. 2011; 31(2):63–67.
24. COAG (Council of Australian Governments) Health Council 2015. Healthy mouths, healthy lives: Australia's National Oral Health Plan 2015–2024. Adelaide: South Australian Dental Service.