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.

<table>
<thead>
<tr>
<th>Response (%)</th>
<th>17.83</th>
<th>36.94</th>
<th>21.66</th>
<th>23.57</th>
</tr>
</thead>
<tbody>
<tr>
<td>Our whole family uses the same dentist</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Our family member with disability has their own dentist, or more than one dentist</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Different family members have different dentists</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No they do not have a dentist</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

FIGURE 2. EASE OF TEETH CLEANING

<table>
<thead>
<tr>
<th>Response (%)</th>
<th>19.51</th>
<th>53.05</th>
<th>27.44</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fairly straightforward</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A bit of a challenge but manageable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely difficult, sometimes impossible</td>
<td></td>
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Asia Pacific Journal of Health Management 2022; 13(2):i35. doi: 10.24083/apjhm.v17i1.815
FIGURE 3. ABILITY AND CAPACITY OF PERSON WITH INTELLECTUAL DISABILITY TO PARTICIPATE IN DENTAL EXAMINATIONS AND TREATMENT

![Graph showing the ability and capacity of person with intellectual disability to participate in dental examinations and treatment.](image)

- **Yes**: 78.85%
- **No**: 21.15%

FIGURE 4. ACCESS TO DENTAL TREATMENT.

![Bar chart showing access to dental treatment.](image)

- Special arrangements were needed to attend the local practice: 14.5%
- Some sedation was needed at the general dentist: 8.2%
- Dental treatment needed to be performed at a day surgery/hospital: 32.5%
- The treatment was effective and completed: 21.8%
- The treatment had to be abandoned due to difficulties: 9.7%
- My family member has not been yet able to access the dental treatment required: 13.1%

FIGURE 5. EXPERIENCE WITH SCHOOL DENTAL SERVICES

![Bar chart showing experience with school dental services.](image)

- We rely upon the School Dental Service for all dental care: 21%
- The School Dental Service is not able to provide care for my child: 64.5%
- The School Dental Service has been flexible and able to assist my child: 14.5%
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.

“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.”

“Attending general practice 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.

“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 consultation 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 traumatizing. 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**


8. Rashid-Kandvani F, Nicolau B, Bedos C. Access to Dental Services for People Using a Wheelchair.