

Health Circle Report

Number 3

Access to Dental Services and Oral Health for People
with Disabilities



DEVELOPMENTAL DISABILITY *wa*

February/March 2016

Access to Dental Services and Oral Health for People with Disabilities

Developmental Disability WA has been hosting opportunities since April 2015 for members to talk about the health issues that affect them and to be part of designing resources, information, skills and education to help members have a strong voice in the health care of themselves or the people they support.

This third Health Circle, Access to Dental Services and Oral Health for People with Disabilities, follows the sessions Finding Unique Access Solutions in July 2015 and Substitute Decision Making in April 2015.

BACKGROUND

Previous Health Circle sessions have demonstrated, through our members and others, that the experience of people with intellectual and other developmental disability in seeking and obtaining health diagnoses and treatment can often be difficult. The challenges experienced can often lead to lack of treatment thereby further exacerbating existing health problems.

A Health Circle session was hosted by DDWA on 22 February 2016, bringing together a panel of leaders in dental services, family members and other interested parties to discuss access to dental services for people with disabilities.

In preparation for the session, a survey was distributed in December 2015 and closed in February 2016, with around 170 respondents sharing their information and experiences. The majority of respondents were parents of an individual with intellectual and other developmental disability. The survey data collected was presented to the meeting to inform participants of the experiences of others and to assist with the discussion.

The survey and discussion addressed oral health along a continuum from home, through check-ups and prevention, general dental care, to major dental procedures. As with other discussions about access to health care for people with disabilities, it was shown that the critical access issue rests in the capacity of the person to participate in receiving dental examinations, diagnoses and treatment processes.

“Autism, sensory overload issues and high anxiety related to any unusual activities mean a full dental exam is almost impossible without general anaesthetic and any treatment, even Xray or scale and clean require anaesthetic.” Response from parent of son with autism and intellectual disability

“Dental treatment anaesthetics are no longer available regularly at [our regional] Health Campus, so would require travel to Perth (not covered by PATS, I believe) As a result it is now more than 7 years since our son had a dental exam and treatment under anaesthetic.” Response from parent of son with autism and intellectual disability

As such, a simple X-ray or examination may be intolerable for a person with a disability, requiring them to be treated in hospital, under anaesthetic. Equally, a person with a profound disability may be able to be treated at a local general dental practice if the practice has the capacity to respond to their need.

THE CONTEXT FOR ADDRESSING ORAL HEALTH

Following the two previous Health Circle sessions and our involvement with the Disability Health Network, state Dental Health Services, and informed by substantial anecdotal reports over many years, DDWA made this issue the focus of the third Health Circle session.

It was recognised that there is no organised oral health-specific consumer 'voice' in the Health or Disability domain in WA to identify unmet needs from the perspective of people and families. There is no community organization or group focused on dental care working to drive reform activity from outside the established service system as it has evolved historically in this state.

DDWA was interested to find out more about the experience of people with intellectual and other developmental disability, in terms of the services that are available to them, the level to which the services that are available meet their needs, the barriers they face and the possible solutions which may be implemented to improve access and overall dental care for people with disability.

"Fine motor skills make it hard for our daughter to clean her teeth properly. Intellectually she thinks if she puts the brush in her mouth then she has cleaned her teeth. We want to encourage her independence with her personal hygiene so are hesitant to push her into allowing her carers to clean her teeth for her. Very difficult situation." Response from parent

"Our family member's disability affects their capacity to participate in dental examinations and treatment because of difficulty following instructions, dealing with discomfort, not fully understanding what is happening." Response from parent

"My family member has not been yet able to access the dental treatment required. Local dentist advised wisdom teeth needed removing. No one wanted to do the procedure." Response from parent

A critical objective of the session was for dental profession representatives, patients, family members and others, to define the gaps and the limitations of the current structures with a view to identifying a platform for systemic reform, if it was agreed that changes were needed.

Do you think dental services for people with a disability living in regional areas will improve? Question from parent

SUMMARY AND CRITICAL THEMES

- ❖ **The home as a setting for oral health services** needs to be explored in respect to prevention and oral health maintenance for people with disabilities. Care in the home could include oral health therapists and dentists providing home visiting services. Oral health therapists are currently prohibited from independent practice however such professionals could provide a targeted service and address this unmet need.

"Training in the skill of teeth cleaning and oral hygiene is very important. A service that provided a therapist or dental nurse to visit people in their homes and teach them to use their own toothbrush, toothpaste, cup etc in their own environment would be really useful. They would be able to learn a routine which would encourage them to have good oral hygiene. Follow up visits until the skill is learned would be ideal." Response from parent

"As part of an organisation, we do like to encourage our clients to access the community whenever possible. But for some clients, it would be useful for accessibility and assistance to have a home visit." Response from support worker

- ❖ **A need to improve access for people who experience anxiety, fear and sensory issues** Evidence from patients and their families, and from dentists, point to a need for an improvement in practice for treating people with a range of needs. In addition there exists a need to improve access for people with particular physical needs such as compromised mobility, as reported by patients and their families, and by dentists. Training through student programs and professional development for existing dentists could enhance access to care at local dental practices.

Private dentists do not appear to enjoy [people with disabilities] attending their practices as they are time consuming, wheelchairs have damaged walls, not enough space in rooms to accommodate wheelchairs. No space for a hoist to transfer client to dental chair. Response from support worker

- ❖ **Examinations, xrays and diagnostic processes present a unique challenge** and can become an obstacle to further care if diagnostic investigations cannot be performed.

PMH dentist have had to sedate child in the past. Special Needs dentist in North Perth have been patient with over a dozen appointments just to have child comfortable in chair and opening his mouth. Response from parent

- ❖ **Improve and increase information about eligibility and appropriate services.** Amongst patients and their families there was a demonstrated need to ensure better information is available, regarding special needs¹ dental services and other appropriate services to provide care to individuals with complex needs. Currently there is no simple way for families to know what services are available and which service model may best suit their family members' needs. This information could be fairly readily placed into a resource for families through a partnership that could include DDWA and the ADA.
- ❖ **Special Needs Clinics.** The single Special Needs Dental Service in North Perth could not meet the demand for service if wider eligibility criteria are promoted to the community. There was also general agreement that not all people with disabilities need to attend specialist (Special Needs) dental services if the mainstream services are willing to be flexible. It may therefore be reasonable to consider establishing a number of Special Needs Clinics dispersed in the metropolitan area. Such clinics could provide both specialist treatment as well as consultancy outwards to private and public clinics, possibly in a 'shared care' model to enable people to receive services closer to where they live.

“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. 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.” Response from parent

“Government dental dentists are very busy, sometimes impatient. Special Needs dental service is amazing, but only accessible to clients that fit their restrictive criteria.” Response from support worker

- ❖ **Special Needs Specialist.** The extent of the current and unmet need for Special Needs services needs to be further explored. The imminent appointment of the first Special Needs Specialist dental practitioner by the Department of Health is an important step towards bringing WA into closer alignment with other jurisdictions nationally and internationally.
- ❖ **Clinical Risks.** Unique clinical risks may exist for people with disabilities that can present greater complications than the dental treatment itself. To quote one panel member, 'once a person is under anaesthetic it is routine dentistry'. Such clinical risks need to be managed, especially post-operatively and in the home.
- ❖ **Benefits of Research.** Research is being proposed to investigate the outcomes after anaesthetic for people with intellectual disability as all advice offered to families about anaesthetic risk is based on knowledge drawn from the general population. The data available in WA enables meaningful research on this particular cohort that would benefit both families and dental professionals.

- ❖ **Hospital-level care, including operating theatre access and post-operative management** is critical for patients unable to tolerate or manage treatment in a dental chair. Access to theatre time is difficult due to the extra time needed pre and post-operatively. Disincentives for private hospitals to make theatre time available need to be addressed through funding arrangements designed specifically for this cohort.
- ❖ **Supporting Dental Practitioners.** The professionalism of dentists and the commitment to provide a service to the community is evident in the anecdotal reports of members who receive good care from their local dental clinic. It is this professionalism that needs to be supported, along with 'special needs' training and possible financial relief, in order to enhance the capacity of General Practice to treat people with disabilities.

“We have a brilliant dentist who used to be a teacher and who has various calming and distracting techniques” Response from parent

PMH arranged all treatment needed - wonderful! Response from parent

¹ Special needs is the term used by the panel of dentists, to describe the diversity of needs, including but not exclusive to patients with intellectual disability physical, disability and or psychosocial conditions.

RESOURCES ALREADY EXISTING WHICH COULD BE BETTER USED

- ‘*your dental health*’ booklet from InclusionMelbourne can be adapted for use in WA to provide an appropriate educational resource for people with intellectual disability and their families
- ADA contact list for WA dental practices can be a means for community sector communication with the dental profession in order to broker access to information for families and individuals
- The Special Needs Dental Clinic in North Perth is a valuable community asset that has broader eligibility criteria than is widely known or understood by the community. Careful promotion of this service, in the context of other initiatives, will enhance access to specialist dental care for people with disabilities.
- The membership of DDWA represents a valuable resource for the dental services sector as partners in advocating for systemic reform if the current working relationships can develop in trust and openness.
- The Dental Act enables some degree of independent practice for oral health therapists that should be actively tested to enable this service to be provided safely to the community.
- The fully developed and costed research proposal into anaesthetic risks for people with intellectual disability could be funded to provide valuable information to the disability and dental communities.

Platform for Change – Our Ten Point Plan

1. Provide good information to families about dental service options so that the ‘market demand’ side of the service equation is strengthened
2. Promote the home as a valid setting for simple oral health assessment and prevention care, including the encouragement of home visiting services.
3. Seek to advance progress towards independent practice for allied dental workers, to enable this group to provide a cost effective service into homes, including group homes, residential facilities and private residences.
4. Build capacity of local General Practice dental services where skills and confidence are the only obstacle to the extension of services to people with disabilities
5. Promote the introduction of Continuing Professional Education in Special Needs Dentistry for the dental profession in WA.
6. Remove price barriers for eligible people with disability by making public treatment cost free
7. Advocate for a system that provides some financial off-set for the extra time that may be needed to treat a person with a disability in private practice.
8. Support dentists with a simple ‘accreditation’ system for those willing and able to provide care to people with disabilities, including through accessible rooms, skilled staff and flexible appointment arrangements.
9. Promote the establishment of 5 Special Needs clinics in key metropolitan locations, where the clinics could provide a secondary or tertiary setting providing expert support, closer to patients’ homes.
10. Promote opening the Skilled Occupations List to Special Needs dental specialists to enable migration of these specialty practitioners into Australia.

