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Es gilt das gesprochene Wort

Swedish experiences of creating services for patients with special needs

The process of developing oral care for people with mental retardation has been a long and hard process. In 1975, it was a hard fight in Sweden for creating a clinic of good standard for these patients as they were not important people in society.

It has been a fantastic experience to follow the development of these peoples' lives. Their lives in Sweden are totally different today and institutions are not even legal for children with mental retardation. However, it took a long time for the government to understand that all children have the right to grow up with their own parents. Today these parents are hard fighters for their rights and needs and sometimes these parents can be rather aggressive if they are not satisfied. For grown-up people with mental retardation there is a law that makes it possible for them to live in smaller assisted accommodations with staff/assistants 24 hours per day. To establish this, laws are necessary. The municipalities are responsible for nursing care for people with disabilities.

There is also a Swedish Dental Act concerning oral health for people with disabilities. This law text is: "Good oral health for all persons on equal terms, with focus on reduce oral diseases. Special attention should be given those with disabilities to have equal good oral health". The Swedish parliament decided in 1998 that the Swedish counties are responsible to fulfil the requirements in the Swedish Dental Act by offering Domiciliary Oral Health visits to people with severe disabilities. It should be done yearly, be voluntary, free of charge, and a dental hygienist should do the oral examination at home. The nursing staff should be present and get information with focus on oral health care. This is free of charge. The dental hygienist performing

domiciliary oral health visits should also offer these patients necessary dental care by a dentist. This care shall contribute to better nutrition and reduce pain and discomfort. It is also possible to offer dental care as a part of medical treatment. To receive this, the dental examination and/or treatment must be of importance for treating the disease, illness or malformation. The referral must come from a medical doctor. The patients' costs for necessary dental care and dental care as a part of medical treatment is only 13 Euro per visit and the high cost limit for medical and dental treatment is 90 Euro per year. The total cost for these activities, inclusive domiciliary oral health visits is 100 milj. Euro.

This law also made it possible to form national odontological centres for people with rare disorders. Mun-H-Center is one of these centres. MHC is a National Orofacial Resource Centre for Rare Disorders and also a National Resource Centre for Orofacial Aids and Appliances for persons with disabilities.

The task is to collect, develop and spread orofacial knowledge about rare disorders and orofacial aids and appliances. To fulfil this Mun-H-Center work a lot with information, education, consultations, treatment, research and development. The team consist of paediatric dentist, hospital dentists, orthodontists, prosthodontist, dental hygienists, dental nurses and speech pathologists and also medical consultants. Mun-H-Center is located at Odontologen in Göteborg and at Ågrenska which is a national family centre for rare disorders situated in the archipelago of Göteborg. Ågrenska arranges 'family weeks', where up to ten families having a child with the same specific diagnosis, come to Ågrenska to stay there for one week. During the week the families get information about the child's diagnosis from different medical professions and form networks for the future. Over the years, Mun-H-Center has become an important collaborator during the family weeks. Ågrenska is today an extremely important meeting place where the users are in focus. This is a fantastic possibility to learn about the orofacial aspects in rare disorders. The dental team have also got new opportunities to meet other medical professionals and inform them about the orofacial aspects which have led to multi-professional cooperation. The team have understood that the mouth is one of the most important part of the human body. It is not hard to understand that orofacial functions are important as we all use

our mouth for breathing, eating and drinking, communication by speech or facial expression and we also use the mouth for our perception. All these functions are dependent on oral health. If you are born with a neurological impairment or malformation, or if you get a disease or a trauma it is a big risk that you will get orofacial dysfunction like breathing problems, eating and drinking problems, motor speech disorder, impaired facial expression, tooth grinding and drooling. It is not hard to understand how these problems inflict in the lives for these families.

During the family weeks at Ågrenska the Mun-H-Center team examine the children with rare disorders and meet the parents. The observation charts and questionnaires are documented in the MHC database and orofacial dysfunctions are very common. This information can be found at Mun-H-Center home page. Orofacial dysfunctions are very usual, 40% have eating difficulties, 52% have speech difficulties, 28% have drooling problems. Even if preventive oral care for all children in Sweden has been extremely successful still many of the children with rare disorders have bad oral health. To be able to help these children, multi-professional cooperation is very important. However the mouth and its function have fallen out of the body and orofacial treatment is not well developed. It is an area that has fallen between the chairs. The medical professionals have little knowledge about orofacial dysfunction and the dental professionals also get very little education in this field. This must be changed and Mun-H-Center work hard to spread this knowledge and to organize better orofacial care.

The vision for the future is good oral health and good orofacial function. Early identification is very important but it is a big risk that children with disabilities meet dental professionals even later than other children. Medical professionals and especially medical rehabilitation centres should of course cooperate with a specialist dental team. Further it is important to focus on preventive oral care so early that we can keep these children healthy. In dentistry we have methods to do this today.

Regular preventive oral care is very urgent for children and grownups with these diagnoses. It is also important that when dental treatment is needed specialists in

dentistry should prioritise patients with disabilities. Parents often describe how hard it can be to get orthodontic treatment for their children and for grown ups it can be hard to get prosthodontics inclusive implants.

Oral motor therapy also needs to be developed in cooperation with speech pathologists and other medical professionals. In the early 1990 a rehabilitation doctor from Argentina came to Scandinavia and introduced the method orofacial regulation therapy. The therapy consists of three parts: physical therapy, orofacial manual therapy and intraoral appliances. By orofacial manual therapy it is possible to improve breathing, muscle tone and to stimulate the facial and oral muscles. Orofacial massage according to Castillo Morales has the purpose to normalise muscle tone and to facilitate facial expression. Dr Castillo Morales also introduced the use of palatal plates for patients with Down syndrome and today palatal plate therapy is frequently used in Sweden with children with Down syndrome and hypotonic orofacial muscles. A positive effect on oral motor development has been shown. Development and research in this area are really challenges for the future.

To fulfil the vision it is also necessary to learn more about the diagnosis and to develop pedagogical strategies for dental treatment. To be successful in examining and treating patients with behavioural problems due to neuropsychiatric disorders like e.g. autism, new pedagogical strategies must be employed also in dentistry. There is well spread knowledge about this in schools, among teachers and other caregivers. Recently a new method, the 1000-learning, was introduced in dentistry in Sweden. The patient comes to the clinic and makes frequent visits on the same day. This method has shown to be very successful for people with behaviour problems. The Mun-H-Center team has also developed special treatment cushions to make it more comfortable to be in the dental chair. These cushions have shown to be very effective and can be found on the Mun-H-Center homepage where a database on aids and appliances for orofacial problems has been established. It is possible to search under the following headings: Oral motor skills, Eating and drinking, Oral hygiene, Activities /treatment.

www.mun-h-center.com

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