Clinical Guidelines & Integrated Care Pathways for the Oral Health Care of People with Learning Disabilities

2001

BSDH

Unlocking Barriers to Care

British Society for Disability and Oral Health

Faculty of Dental Surgery

The Royal College of Surgeons of England

Diana

THE WORK CONTINUES

Funded By: Diana Princess of Wales Memorial Fund

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Contents

Executive Summary

A number of reports have examined the needs of people with learning disabilities. These guidelines focus on oral health care and how it can be improved through an integrated care approach. They target a wide audience and should be of use to all those concerned with the health and welfare of people with learning disabilities.

Evidence confirms that people with learning disabilities' uptake of screening services is lower[1-3] and that they have poor oral health when compared to the general population. Good oral health is linked to good general health and a number of systemic diseases have oral manifestations[4]. Improvements in oral health care can be obtained by encouraging carers to regularly examine the mouth of the person they are caring for. Completing an oral assessment will help to identify any changes in the mouth. This can aid diagnosis and treatment if reported to the dentist at an early stage.

The guidelines are based on published evidence and follow the format of other clinical guidelines developed by the Faculty of Dental Surgery The Royal College of Surgeons of England and those from the British Society of Disability and Oral Health. Information was gathered from consultation groups of people with mild to moderate learning disabilities. Postal questionnaires were also used. The full guidelines will be available on the Royal College of Surgeons of England website www.rcseng.ac.uk, and the British Society for Disability and Oral Health website www.bsdh.org.uk.

The main emphasis of the guidelines is on the prevention of oral diseases. The recommendations made for all age groups are: dietary recommendations that are in line with healthy eating policies[5]; a good oral hygiene regimen with the use of fluoride toothpaste and regular visits to the dentist. In the pre-school and school age child recommendations are made to use fluoride and its supplements[6], together with fissure sealants where appropriate. These are the key messages for health care professionals and carers for the person with learning disabilities (Section 3).

Practical information on the provision of oral health care, which is aimed directly at the service user, parent and carer, is given in Section 4.

Section 5 covers the issues of commissioning oral health care services for people with learning disabilities with the emphasis on the prevention of oral and dental diseases.

Training for the health care professional at undergraduate and postgraduate level involving the provision of care for people with learning disabilities needs further development. The training process needs to be extended to carers, most of them do not have any form of training in oral care. (Section 6).

There are added problems for care providers and carers when caring for someone who does not have the capacity to give informed consent. Section 7 clarifies these points in accordance with current law in the United Kingdom.

The role of voluntary organisations concerned with the welfare of people with learning disabilities is covered in Section 8.

Suggestions for areas of further research are discussed in Section 9.

Section 10 covers the resources section and gives details of further information available from organisations that have developed material aimed at people with learning disabilities.

The glossary in Section 11 explains some of the terms used in these guidelines.

This is a living document that will be reviewed in the light of further research and development.

Completion of the enclosed evaluation form will help to determine the effectiveness of these guidelines.

Foreword ‘A Parent’s’ View’

The realisation that your child is likely to have a severe learning disability is a traumatic experience for any parent. Our daughter, Anne, was born in September 1966. She seemed to be quite normal in all respects until at six months we thought her progress was slow compared to our two boys. Our GP said not to worry, “She is just slow!” However we insisted things were not right and when Anne was eleven months she saw a paediatrician who diagnosed she would be handicapped probably due to a chromosomal abnormality. How you deal with the shock of that news is dependent on many circumstances including the way in which you are told and supported by the professional people involved; the nature of the handicap and your ability to rationalise with the situation.

Once the initial shock subsides, it is not unreasonable that you will expect that there will be a high level of expertise, knowledge and services geared to helping you raise and educate your child and, in adult life, to provide good day care, respite and ultimately residential facilities. Sadly, this is not always the case. There are of course many examples of good practice, but there are also far too many instances where services for people with learning disabilities are relegated to a ‘Cinderella’ status because of insufficient resources.

Good oral and dental care is important for us all. We first became aware of the importance of good oral health for someone with a learning disability when a dental hygienist addressed the local MENCAP meeting. Given this importance, it is amazing that so much is left to chance. General training in hygiene and the provision of specialist hygienists, nurses, dentists and anaesthetists is very patchy indeed. In most cases, it is the care parents give in the early stages that will determine good dental health in later years, but they also need training and support.

Anne is now 34 and in full time residential care. She is severely handicapped with little speech, but she does have the great ability to bring a sense of happiness to everyone she meets. She would be unlikely to initiate, or maintain, an oral care regimen on her own and it is thanks to the help of many people over the years, that her oral health is good today. If that help had not been there then, almost certainly, she would have suffered early loss of teeth and gum disease with a consequent adverse effect on her digestion, enjoyment of food, general health and social acceptability.

As a parent, I hope these guidelines will focus the necessary attention of everyone concerned with the wellbeing of people with a learning disability on this important subject.

RON FRANKLIN

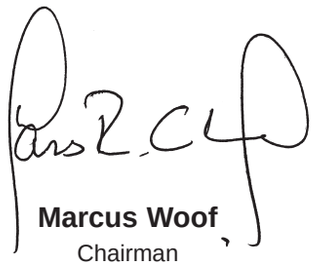
Why Oral Health Care Guidelines?

Diana, Princess of Wales was made an Honorary Fellow in Dental Surgery of The Royal College of Surgeons of England in 1988 in recognition of her involvement in health care. Her interest in the needs of disadvantaged groups in society and the work of the Community Dental Service in this area resulted in a successful grant application to fund this project from the Diana Princess of Wales Memorial Fund.

These guidelines are a joint initiative between the Development Group for Community Dental Practice of the Faculty of Dental Surgery of The Royal College of Surgeons of England and the British Society for Disability and Oral Health. The aim is to improve the oral health for people with learning disabilities by increasing the knowledge and skills of all those people involved in the provision of care.

The members of the Development Group for Community Dental Practice are dentists from the Community Dental Service who are charged with developing a collegiate home for community dentists, with the aim of promoting and maintaining high standards and quality of patient care.

The British Society for Disability and Oral Health aims to bring together all members of the dental team with an interest in the care of people with an impairment or disability. The aim of the organisation is to promote good oral health by studying the provision of oral care, developing both undergraduate and postgraduate education and training and encouraging research in the field.



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Research Methodology used for the Development of these Guidelines

1. Systematic review of the literature was carried out, which examined several data bases, that included Medline, Bids, Cochrans, SOSIG, Embase and the University of York web-site.

2. Guidelines produced by the Royal College of Surgeons, the British Society for Disability and Oral Health and other bodies were included in the literature review.

3. Consultation groups based on focus groups techniques were set-up in Scotland, England, Wales and Northern Ireland, which involved people with learning disabilities, parents, professional carers, Residential Home Managers, and members of the dental profession to obtain their view on oral health and dental services in their area.

4. A Questionnaire was designed and sent out to people with learning disabilities via MENCAP, ENABLE and the Downs Syndrome Association, Bexley Learning Disability Team to give further information on the perception of oral health of people with learning disabilities. This questionnaire was analysed using SPSS.

How to use these Guidelines

The object of these guidelines is to provide the evidence for the foundation of local guidelines and protocols, which improve the oral health of people with learning disabilities. They focus on both professional and multi-disciplinary care for people with learning disabilities.

The guidelines are therefore aimed at everyone involved, service users, their parents, carers and advocates, health and social service commissioners and providers, dental and health professionals, education and training establishments, private and voluntary sector organisations, planners and politicians.

It is hoped that all the subjects and material will be of interest to you, and will be read accordingly but because of the comprehensive and diverse nature of the guidelines you may find that some sections are more relevant to you.

To help you find which of the sections are of most interest to you: -

- Please refer to the contents page, which will give details of the sections.
- For ease of identification, each section is colour coded and this colour will appear on the edge of each page.
- Recommendations will be found at the end of each section. The recommendations are graded for level of evidence. Details of the method of grading are given on the inside fold of the front cover of these guidelines.

1 Introduction

Although people with learning disabilities have the same right to equal standards of health and care as the general population, there is evidence that they experience poorer general and oral health, have unmet health needs and have a lower uptake of screening services. The impact of oral conditions on an individual's quality of life can be profound[7]. Poor oral health may add an additional burden whereas good oral health has holistic benefits in that it can improve general health, dignity and self-esteem, social integration and quality of life [8]. Further, those people with oral and facial developmental abnormalities may have additional needs requiring special care[9].

Data available on oral health status relates mainly to specific groups. The overall picture is one of poor periodontal health and a greater than normal unmet need of treatment for children and adults (Section 3). Oral health may be further complicated by medical or behavioural factors and their treatment[10]. This document provides guidance for the development of clinical care pathways and local standards for oral health care in order to raise the oral health status of this group to at least the standard of their non-disabled peers and addresses the inequities they experience. It is recognised that different oral health needs and different problems can arise at different ages in the lives of people with learning disabilities. Where appropriate, this document will make specific recommendations for each of these groups and suggest how the transition between these age categories may be best managed.

The following definitions will be used:

Learning disability has been described as "a significant impairment of intelligence and social functioning acquired before adulthood"[11]. People with learning disabilities is the term that will be used throughout this document.

Health "A state of complete physical, mental, and social well-being, rather then solely an absence of disease"[12].

Oral health "is a standard of health of the oral and related tissues which enables an individual to eat, speak and socialise without active disease, discomfort and embarrassment and which contributes to general well being"[13]. The term 'oral health' includes dental health and will be used throughout the document.

Prevalence of Learning Disability

It is estimated that over one million people in the UK have a learning disability ranging from mild impairment to approximately 200,000 with a severe or profound disability[11]. More males than females are affected with about one quarter being children aged under 16. Approximately a quarter of the total population with learning disabilities are profoundly disabled with additional disabilities. There has been little change in the number of people known to have learning disabilities aged over 20 years and a small increase in the number living at home, with a migration from hospital to community accommodation.

Medical Problems

People with learning disabilities have an increased prevalence of associated disabilities such as physical or sensory impairments, behavioural problems and epilepsy, which increase their health needs[14]. Forty percent of people with Down's Syndrome suffer from congenital heart defects and immunosuppression. These factors have an impact on oral health and dental management[9]. Schizophrenia, delusional disorders, autism and behaviour disorders are similarly reported[15], with a higher rate of dementia among older people with learning disabilities than the general population[16]. Fifteen per cent of adults with learning disabilities are over 65 years old. Inability to cooperate for dental treatment can lead to a significant need for treatment under sedation or general anaesthesia, and alternative techniques for behavioural and anxiety management[17]

Patterns of Care and Support

Patterns of care and support for people with learning disabilities underwent major changes in the twentieth century. The concept of normalisation, reinforced by legislation[18], led to closures of long-stay institutions and transfer of residents to smaller homes in the community with a change in emphasis and responsibility for

care and support from health to social services. However, the development of services has been inconsistent, leading to national, regional and local variations in health, social care, 'not for profit' and commercial support systems with most residential places now provided by the private or voluntary sector.

Rejection of the medical model of care has resulted in some loss of focus on health[1]. Adherence to a social model needs to include appropriate attention to health, both in terms of life-style and access to health services[19]. While the primary need of adults with learning disabilities is for social care, they also need support from health professionals[20]. Without the encouragement and active intervention of carers, many would not gain access to basic health services[8].

The changing role of special schools and adult services has led to greater integration into main-stream education, community projects and employment. This has created new challenges as traditional methods of service delivery may no longer be considered acceptable[21]. An understanding of the organisation of local patterns of education and support for transition to adult services is essential in order to target services at the most vulnerable people. The need to collaborate with specialist services is self-evident. However, since most people with learning disabilities live in their own homes, a networking approach with health, statutory and voluntary agencies providing care and support, is a primary requirement.

Philosophies of socially valued roles and social integration[22] have led to encouraging changes to support people with learning disabilities achieve their full potential in society[23]. Joint Care Planning Teams have been developed to facilitate inter-agency working and overcome barriers[24]. The provision of Community Care services is now shared between health, social, voluntary and private agencies. However, health and social services have been found to have differing expectations[20]. This document aims to support and facilitate inter-agency collaboration by addressing the oral health needs and demands of people with learning disabilities.

Changes in attitudes and policy have led to the assertion that people with learning disabilities are entitled to the basic human rights accorded to all members of society including:

- Recognition that they are individuals.
- A place to live of their own choice.
- The right to participate in decisions, which affect their lives.
- Access to the amount of support it takes to enable everyday living, which includes adequate health care [25].

The development of community care has created issues of choice and quality of life, which are central to addressing improvements in oral health care[26]. Integration has an increasing impact on service development with concern that de-institutionalisation will result in reduced frequency of contact with dental services and deteriorating oral health unless these problems are addressed[9;27]. Ninety per cent of children and sixty per cent of adults living at home rely on family members or carers to access basic health services[28]. Their needs must also be considered when developing services.

Oral Health and Quality of Life

Two quality of life measures are currently used to assess the impact of oral health status. The medical model uses the absence of disease, whereas the social model measures well being and emotion[29]. The emerging consensus highlights eight core areas; emotional well being, interpersonal relations, material well being, personal development, physical well-being, self determination, social inclusion and rights[29;30].

Quality of life issues are increasingly important in the debate about the aims and effectiveness of services for people with learning disabilities[31]. Emphasis has also been placed on the importance of subjective indices[29] since such assessments are regarded as being central to an authentic model that respects the aspirations of the individual[31].

Health related measures use three dimensions; physical symptoms, perception of well being and functional capacity. In terms of oral health, quality of life could be measured by the number of dental symptoms, perception of oral well being and social and physical oral function[32]. Models for assessing quality of life need to bring together the medical and socio-environmental approach, which combines effect of disease and non-medical factors[33]. Such a model may then lead to identifiable dimensions for quality of life in relation to oral health. Research in this area in relation to learning disability is in its infancy and needs further investigation.

Summary

It is clear that, whatever the nature or degree of disability, people with learning disabilities have the same rights as all other members of society.

Dental services should be provided in a way that:

- Recognises that they are individuals.
- Recognises their right to participate in decisions that affect their lives.
- Provides the amount of support necessary to enable everyday living, including adequate health care[25].

'Oral health and quality oral health care contribute to holistic health. It should be a right not a privilege'[34]

2
Barriers to Oral Health

The barriers to oral health that people with learning disabilities experience will vary by age and the level of parental or social support received. These change throughout life with particular problems associated with transitional periods.

Attitudes to oral health, oral hygiene and dental attendance and the relative value placed upon these factors must be viewed in the context of illness, disability, socio-economic status and the stresses imposed upon daily living for the individual, family and carers [9]. Oral health may have a low priority in the context of these pressures and other disabilities, which are more life threatening[35]. Hence it requires a change in attitude and practice for parents/carers to include oral health as part of routine care[36]. Routine oral health care improves comfort, function and self esteem and reduces the need for extractions rather than fillings and a crisis management approach for pain relief, sometimes requiring general anaesthesia.

2.1 User / Carer Barriers

An individual's physical, mental and cognitive ability to carry out effective oral hygiene, make choices about healthy eating, seek dental services or co-operate with treatment are factors that influence oral health. Barriers to accessing and using dental services include lack of perceived need, inability to express need, and lack of ability for self-care[37].

Parents/carers face challenges in providing a recommended healthy and nutritional diet for an individual with eating, drinking difficulties. In addition, a necessity for high energy food supplements, sugar based liquid medication and laxatives will increase the risk of dental caries. These problems can be countered by enlisting the help of parents and carers and the dental team to instigate programmes to prevent oral diseases as part of the person's daily routine. Since poor standards of oral hygiene exist in all age groups [37; 38-49], parents and carers are likely to need training to carry out these programmes effectively.

The majority of people with learning disabilities have poor verbal skills and are restricted in their ability to communicate their needs[2], possibly only being able to manifest their discomfort or pain through changes in behaviour. Very young children also lack verbal skills and so may not be able to explain toothache or complain of pain[50].

Fear and anxiety are the most common barriers to dental care[51] and people with learning disabilities are no different from the wider population in this respect[1, 52-53]. However, it may be harder to discuss and resolve those fears. Dislike of dental treatment is significantly related to irregular dental attendance[49]. Inability to co-operate with treatment leads to a greater need for behaviour management techniques, conscious sedation and general anaesthesia than for the general population[38,43; 52; 54; 55].

Policies for self-empowerment, freedom of choice and restraint create problems for dental attendance[47; 56], with many service users unable to seek care without support[57]. Lack of parental awareness is a major contributory factor for low dental attendance in children[58] generally. However children with learning disabilities are less likely than their contemporaries to have had a dental check-up in the previous year[59]. Greater travelling distance, because the disabled child requires special care and appropriate services that are not available locally, may also contribute to less frequent attendance[60].

Community home managers often identify residents' reluctance to accept care as being a barrier to dental attendance[61]. Poor uptake of dental services is reported when the onus for accessing care is transferred to adults with learning disabilities and their support workers, even when there is a high level of support from the dental team[62].

The knowledge and skill of carers, whether family or professional, have an impact on oral health and their perception of need may influence the frequency of contact with dental services. Their knowledge and practice of oral health care has generally been demonstrated to be inadequate[63-67] thus there are basic oral healthcare training requirements.

A lack of relevant vocational qualifications and high staff turnover in supported accommodation provided by voluntary and private organisations have implications for staff training[68]. These needs are addressed in guidelines developed by the British Society for Disability and Oral Health[8] . Training programmes should stress that poor standards of oral hygiene can be a serious health threat[69-71] and should address the needs of all grades of staff and shift patterns[72,73]. Providing training alone is not sufficient to promote behaviour change and the attitudes and values of carers also need to be addressed[74]. The large increase in numbers of support workers in the community and staff turnover provides a major challenge for the provision of oral health education and oral health care for people with learning disabilities.

2.2 Professional Service Providers

Community Dental Services (CDS) and some dentists in the General Dental Service (GDS) treat and care for different populations of patients with special needs and a continuum of service provision potentially exists [75]. However, previous surveys of new dental graduates have demonstrated low confidence scores in the management of such patients[76] and inadequacies in professional training for dentists and hygienists have been reported[77,78]. Dentists' lack of experience of learning disabilities and the financial constraints of the system of remuneration in the NHS may be contributory factors[55]. Carers believe that, on the whole, dentists prefer not to see patients who may present a problem to them [1].

The Disability Discrimination Act (1995)[79] now makes it unlawful for a service provider to treat a disabled person less favourably for a reason related to their disability. This includes refusing a service, treating an individual less favourably in the standard of service or the manner in which it is provided or providing a service on less favourable terms[80]. The Act applies to all health care and includes the provision of dental care.

Since previous experience of treating members of these groups tends to create more positive attitudes[75], suggestions have been made to improve the situation[81]. This includes more and better under- and post-graduate dental training, and discretionary fees to compensate for any additional time required. The need for special skills and experience for the treatment of patients with severe or complex disabilities, and an accepting attitude and partnership with carers is recommended by care managers[61]. Training in the care of people with disabilities should be available for all members of the dental team[82], although it has a low priority in many dental schools[83].

Specialist training does not as yet include Special Care Dentistry although specialist training in Paediatric Dentistry includes the management of children with a learning disability. Specialist training and registers in Dentistry are a recent occurrence. Whilst there is as yet no specialist registration, a Joint Advisory Committee in Special Care Dentistry has been established to develop training and career pathways in Special Care Dentistry which will encompass the management of children and adults with disability.

2.3 Barriers to Accessing Oral Care

A large number of people with learning disabilities also experience mobility problems. Physical access to dental services is a major barrier to accessing dental care[56;56;84;84;85]. There may be significant costs in terms of physical effort; emotional effort and financial outlay to gain access to oral care[86].

Data gathered from the consultation groups during this project found people with learning disability were aware of the importance of oral health, oral hygiene and diet. Either their parent, carer or the dentist (via a reminder letter) arranged attendance for oral care. Their perception of oral health was quite good. Despite this all the participants had experienced some tooth loss, through extractions or teeth falling out due to "bad gums". The questionnaire results showed similar responses to the consultation groups with those in work having a more positive attitude towards oral care.

2.4. Ethnic Issues

People from ethnic minority groups are subjected to the same barriers to oral care but these may be exacerbated by factors related to ethnicity[87]. There are different customs and practices between cultures and it is important to be aware of them. People from ethnic minority groups may have different attitudes to and beliefs about oral matters. Females may prefer to be seen by a female dentist[88]. Dental disease may not be seen as a chronic process but more as an acute episode and there may be a tendency to attend the dentist just for the relief of symptoms[87]. Oral health promotion and acclimatisation to the dental environment are, therefore, very important for this group. Cultural variation in ethnic minority groups, who may have difficulty in communicating their needs, may act as a barrier so attendance at the dentist does not match their need. There is an expectation that the number of people with learning disabilities from ethnic minority groups will increase[89]. Learning disability can exacerbate the barriers to oral care that already exist for some people from ethnic groups.

Multicultural education packages should be used to ensure that appropriate oral health messages have been delivered. There are some packages available including the Homefirst manual and oral health leaflets published by Mencap (Section 10, Resources) but more need to be developed.

3
Improving Oral Health through Clinical Guidelines and Integrated Care Pathways

3.1. Oral Health Care of the Pre-school and School Age Child

Introduction

It is well documented in consecutive national surveys of dental health that there are significant regional variations in dental caries experience in children in the United Kingdom. This has been attributed to many factors including water fluoridation, social class, local cultural eating habits and provision of preventive health care. Such variation may indicate a different emphasis of oral healthcare between regions and one recommendation may not be appropriate for the whole country.

There is little difference in the prevalence of dental caries (decay) between disabled and non-disabled children. However more decayed teeth remain untreated and teeth are more frequently extracted in children with a disability[40; 45, 48; 90-92].

Variations in dental caries prevalence occur in relation to the nature and severity of the child's disability, residence and access to dental services. Lower levels of untreated decay in children at special schools are attributed to the fact that a high proportion (85%) received treatment from the Community Dental Service [93]. In institutions, lower dental caries prevalence may be related to restricted access to a cariogenic (high sugar) diet[38]. Children with Down's Syndrome have a lower prevalence of dental caries due to later tooth eruption and abnormal tooth morphology[94-96]. In children with mild learning disabilities and children who are partly independent, dental caries prevalence is higher[91,97]. It would appear that these children may have fewer dietary restrictions and are therefore at greater risk of dental caries.

All studies report uniformly poor standards of oral hygiene and plaque control, and poorer periodontal health in children with learning disabilities[38; 40; 45; 48, 90-93,97]. A high proportion of children in special schools have periodontal disease[48; 93]. Gingival hyperplasia (over growing) affected 20% of children with a severe or profound learning disability[38]. Children with milder learning disabilities not receiving treatment have the poorest gingival health[91]. Gingivitis (inflammation of the gums) and periodontal disease is more severe in children with Down's Syndrome even when a good standard of oral hygiene is maintained[38].

The key to good oral health is the involvement of parents in the early implementation of preventive practices including good dietary habits, appropriate fluoride therapy, fissure sealants and effective oral hygiene[6].

The dental profession has a particular responsibility to raise awareness of the need for early and regular contact with dental services for children with learning disabilities, not just with parents, but also with the range of other health-care professionals involved with the child.

Children with learning disabilities are in contact with a range of health professionals[45] (*Figures 1 and 2*). Education coupled with close collaboration with specialist services[98] facilitates the early identification of children who may be at risk. Ideally, a dentist should be included in the inter-disciplinary team[9], ultimately resulting in more comprehensive and cohesive care. However, the changing role of special schools and integration into mainstream education create challenges for identifying such children[21].

Prevention and Promotion of Oral Health

The benefits of fluoride for the prevention and control of dental caries are well documented[6]. Optimising fluoride in drinking water remains the cornerstone for prevention[99] but in its absence, dietary fluoride supplements, fluoride toothpaste and topical applications are recommended[6, 100].

Diet

Sugars are not only detrimental to oral health, but can also have a negative impact on general health[101]. Dietary advice should not be given in isolation but in the context of policies for healthy eating. It is important to provide simple, practical and realistic guidance for selecting a balanced diet[5].

When a high calorie intake is recommended to maintain nutritional status, intensive preventive techniques are recommended. Collaboration between dentists and dieticians will ensure that appropriate preventive advice is offered. General medical practitioners should be aware of the oral health risks of long term sugar based medication[101] and where possible prescribe sugar free alternatives.

In pre-school children, the consumption of sugars is double the recommended maximum[102]. Feeding difficulties, food supplements and sugar based medicines increase the risk of dental caries. There is therefore a clear need for the dental profession to be more actively involved in dietary counselling and provision of preventive oral healthcare and treatment[45].

For children at risk of dental caries (which includes children with learning disabilities), National Guidelines recommend completion of a 3-4 day dietary diary, dietary counselling with limited achievable targets and regular monitoring of compliance[6].

Use of Fluoride

Children with learning disabilities are in a high-risk category for dental caries, and the principles that apply to pre-school children, apply equally to older children and adolescents[6]. Recommended doses of fluoride supplements or mouthrinses will depend upon the levels of fluoride in drinking water. However, mouthrinses are not recommended for people with swallowing difficulties. Children may also benefit from the application of professionally applied fluoride varnishes.

Fluoridated Toothpaste

All children should regularly use a fluoride toothpaste according to the manufacturers' and dentists' instructions[6]. It is the maximum amount of toothpaste ingested rather than the frequency of ingestion that is the most important factor in reducing the risk of enamel opacity. As children tend to spread toothpaste over the whole bristle area, controlling the size of the brush head is important. Older children may be at greater risk of ingesting toothpaste; therefore adult supervision is essential to monitor the quantity of toothpaste used[103].Toothbrushing should be supervised up to the age of 8 years, but for children with learning disabilities, this may be necessary even into adult life.

Fluoride Supplements

Dietary fluoride supplements should be considered for children at risk of dental caries in areas where there is no more than 0.3ppm in the drinking water (*Table 1*)[6; 104]. The small potential risk of mild enamel opacities may be outweighed by the benefits of fluoride supplements. However, fluoride supplements demand a high degree of compliance over a long period. Consideration should be given to the most appropriate or acceptable method of delivery, whether as fluoride drops or as tablets. Whatever the delivery method, maximum doses should not be exceeded[99].

Table 1. Recommended use of fluoride supplements

Age	Concentration of Fluoride in drinking water		
	ppm less than 0.3	ppm 0.3-0.7	Tablet equivalent
0 – 6 months	0.00	0.00	0.00
6 months to 3 years	0.25mgF/day	0.00	Quarter of a tablet per day
3-6 years	0.50mgF/day	0.25mgF/day	Half/Quarter of a tablet per day
6 years & over	1.00mgF/day	0.50mgF/day	One/Half of a tablet per day

If fluoride level in the water is 1ppm or more then no supplements are necessary.

Professionally Applied Topical Fluoride Treatment

Topical fluoride varnishes are of proven benefit in preventing dental caries and in helping to arrest dental caries in children with 'nursing bottle dental caries' and cervical decalcification. These are highly concentrated methods of providing fluoride and the recommended dose must not be exceeded[99].

Oral Health Education

Poor standards of oral hygiene and plaque control and poor standards of oral health are reported in disabled children[90]. Poor motor control, imbrication of teeth, lack of cleansing and food clearance can lead to accumulation of food debris. Mouth breathing reduces the protective function of saliva on tooth surfaces and gingivae.

Toothbrushing is essential to remove plaque and food debris, and maintain gingival and periodontal health. The technique is less important than the effectiveness of plaque removal. Parental support and assistance for toothbrushing may be required throughout childhood. Assessment of a child's oral hygiene skills by the dental team may be necessary to ascertain the child's ability to be self-caring. However, all children should be encouraged to brush their own teeth, even if support and assistance are required. The dental team needs to be sensitive to the everyday problems and difficulties encountered by parent/carers in implementing an effective oral health care routine. A dental hygienist or therapist has a major role to play in motivating, providing reassurance, support, specific advice and training for individual problems.

Early Periodontal Problems

A number of studies[90; 105] have indicated that children who have learning disabilities have more plaque on their teeth and more gingivitis, than the general population. There is a marked increase with increasing age and the poorest periodontal health is found in the 16 – 19 year age range[105].

Children with Down's Syndrome are susceptible to a more generalised aggressive form of periodontitis due to immunodeficiency resulting in bone loss and deep pocketing. The progress of this disease involves a period of acute inflammation and possibly pain. If untreated, the disease will result in tooth loss.

Education and Training: Parents Carers and Professionals

The process of improving the oral hygiene of children with learning disabilities does not lie solely with the dental profession. It requires an integrated approach involving the child, the parents/carer/advocate and dental personnel.

A child suffering dental pain, who is unable to express discomfort may exhibit a change in behaviour which may include any one of the following: loss of appetite, unwillingness to participate in usual activities, disturbed sleep, irritability, self injury. It is important for parents, carers and the dental team to be alert to such changes in behaviour and eliminate oral or dental pain as a possible cause of behaviour change.

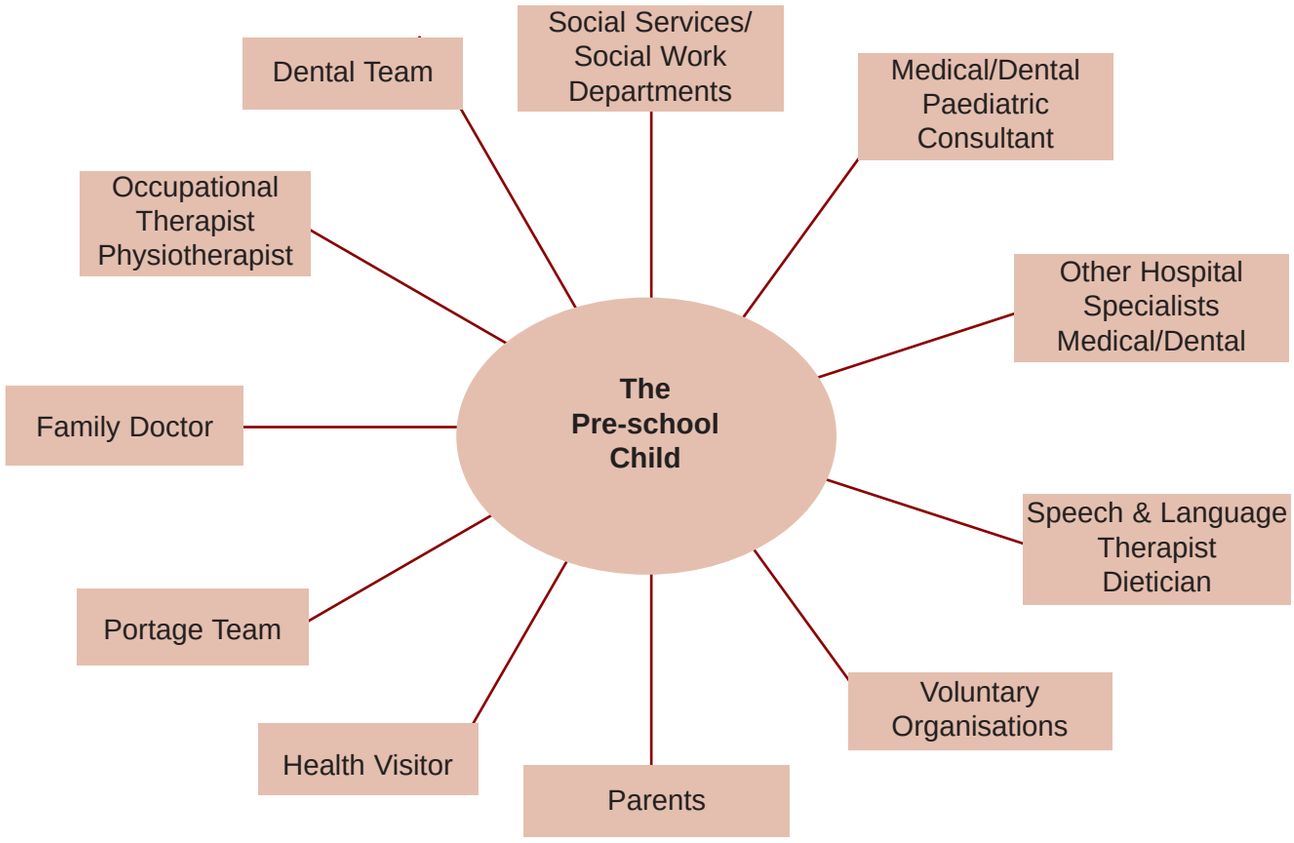


Figure 1. Integrated Care for the Pre-school Child

Integrated Care for the Pre-school Child

There are clear recommendations for a co-ordinated approach to sharing information amongst all providers of specialist services[106]. General Medical Practitioners may have a key role as gate-keepers to secondary care and have expressed a need for more information on the availability and access to specialist services. Health Visitors are an important point of contact for parents of babies and toddlers and are in an ideal position to offer preventive dental advice at an early stage in the child's development[107]. However, such advice may be missed if parents are perceived to be unreceptive[108].

Identification of oral health needs as part of general healthcare needs assessments facilitates early contact with dental personnel. Health Authorities have a responsibility to disseminate information and facilitate these processes through the resources of the Community Dental Service (CDS) and Hospital Dental Service (HDS).

Example of Good Practice

Questions on dental attendance are included in the Cardiff Health Check, which is designed to assist general medical practitioners to assess people with learning disabilities[109].

Working positively with the health visitors increases registration of pre-school children attending the CDS[110].

Initial Visit

The first contact with dental services is critical as it provides the first opportunity for the dentist to establish a relationship with parents and the child and provide preventive advice. In some cases, a home visit may be more helpful to families and provide the dentist with more information on the possible barriers to care. Introduction to the dental environment at an early age may help to facilitate subsequent care, although acclimatisation may take longer and require more frequent visits.

Example of Good Practice

The establishment of the mobile dental service for children requiring special care and the development of training programmes for carers and the dental team[111].

A consent form for the Community Dental Service in the child's health record encouraged health visitors to gain consent for advice and referral[112] for oral care.

Regular Attendance

The majority of children with disabilities use the Community Dental Service but less than half attend regularly[60]. Children who only attend when in pain have been found to have more decayed and missing teeth and fewer fillings than regular attenders[60]. The evidence points to the need to increase regular contact with dental services.

It may be difficult to identify the origin of a child's dental symptoms, a problem that may be exacerbated in children with learning disabilities who may be unable to communicate effectively. Regular contact enables the dentist to monitor the situation and become more familiar with a child's behaviour changes that may indicate an oral problem. It allows the child to become familiar with the dental staff and surgery.

The School Age Child

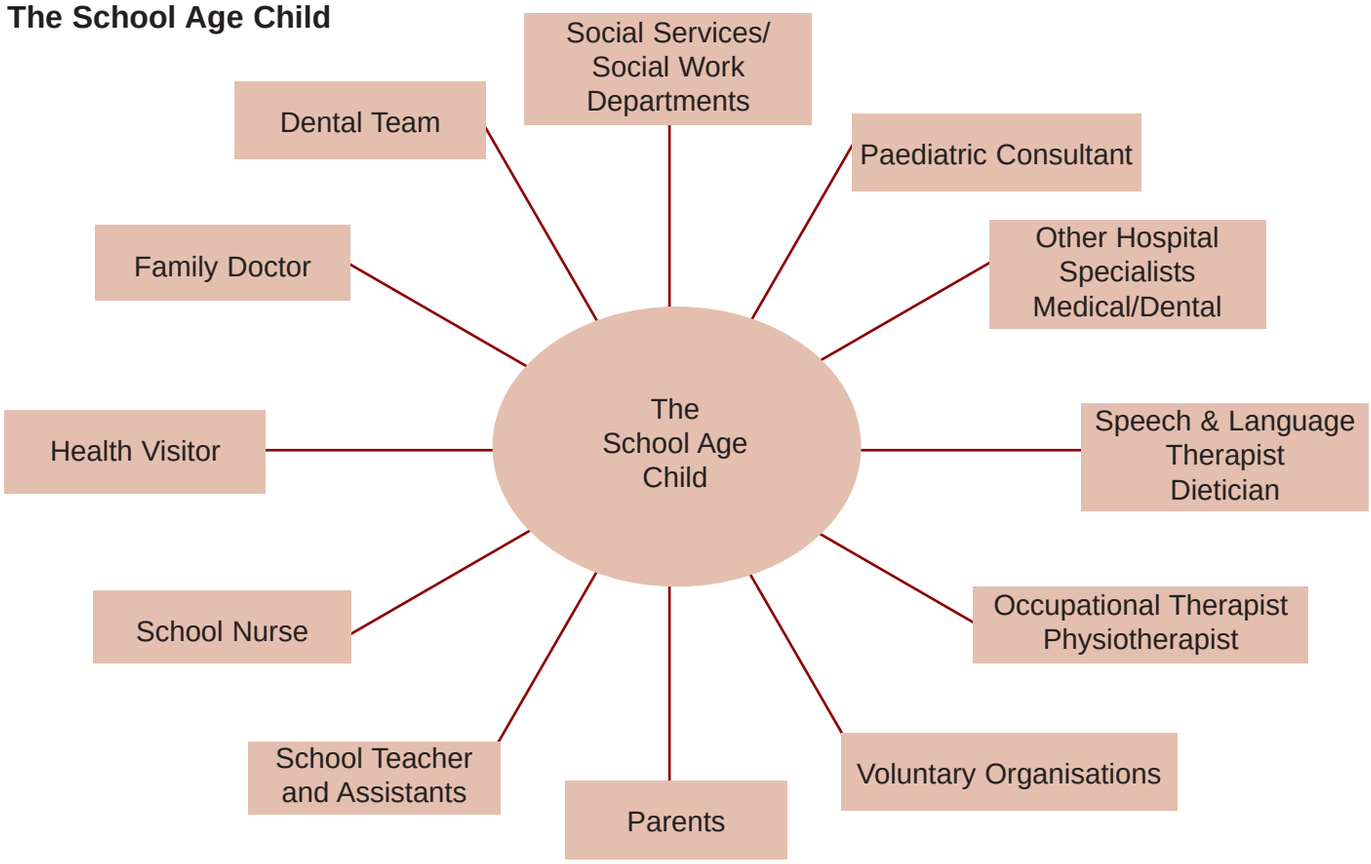


Figure 2. Integrated Care for the School Age Child

Oral Health Screening, Assessment and Dental Services

Screening programmes aim to identify the oral health needs of children and are carried out by the CDS in compliance with health directives[113]. Screening is carried out on at least three occasions during a child's school life. In special schools, this process may be more frequent.

Integration into mainstream education presents challenges for dental services in targeting children with disabilities, as services offered need to be non-discriminatory. Traditional methods of service delivery using mobile dental units, just for special units, may no longer be acceptable in this context. However, mobile dental services can help parents who have difficulties in reaching fixed dental services.

Working with Schools

Positive links between educational establishments and dental services are essential to promote the oral health of children with learning disabilities. Programmes, which include oral hygiene in a child's Individual Educational Plan, should be encouraged. The initiatives may fail due to the pressures upon staff imposed by the National Curriculum.

Vending machines are increasingly used for income generation. This allows pupils to purchase drinks and snacks during the day, and between meals. Many of the snacks available cause dental caries and erosion. This should be addressed and discouraged by health education campaigns in the context of healthy eating policies[114].

Oral Care and Treatment Strategies

Careful assessment of a child's dental needs and ability or willingness to co-operate during treatment is essential. This is equally true for children with learning disabilities. Home visits and de-sensitisation programmes may be necessary to achieve this. An accessible, safe and welcoming environment and team approach will help to reassure the child and parent. Continuity of dental personnel, a consistent approach and clear explanations of each step of treatment help to overcome anxieties. The training needs of the dental team in recognising the emotional and psychological concerns of the child and their family need to be addressed in achieving these standards. Treatment planning should be realistic and appropriate to the child. With time, patience and an experienced dental team, most children with learning disabilities will accept routine dental care. However, some children may require sedation or general anaesthesia to achieve an optimal standard of treatment. The use of general anaesthesia should be a last resort and only undertaken when all other avenues have been explored[115].

Fissure Sealing

Children requiring special care are a priority group for the use of fissure sealants[6]. However, the success of this treatment depends on patient compliance.

Example of Good Practice

Protocol for Dental Needs Assessment of Special Needs Children to assess co-operation towards dental treatment in order to determine patient management has been developed by The Department of Community Dental Health and The Department of Paediatric Dentistry at GKT King's College London (Denmark Hill Campus).

A tooth-brushing programme at a school for children with learning disabilities produced long term improvements in oral hygiene as a result of enlisting staff support to help and encourage children[116].

Orthodontics for Children with Learning Disabilities

Orthodontic intervention in the developing dentition aims to achieve the optimal occlusion (in terms of dental health and aesthetics) for the individual. Such intervention may involve the elective extraction of primary or permanent teeth and the use of orthodontic appliances.

Appliance treatment is dependent on patient co-operation. The patient must be able to wear and care for an appliance and maintain excellent oral hygiene. It is not sufficient that the parent is enthusiastic. Children with mild learning difficulties often co-operate well whereas those with more severe problems may have difficulties. Embarking upon a treatment, which is beyond the patient's ability, may result in a dental state, which is worsened rather than improved, particularly if extraction of permanent teeth is involved[117]. Appliance therapy should be limited to simple movement e.g. correction of an incisor in cross-bite, if the patient's co-operation is poor.

3.2. The Transition Stage

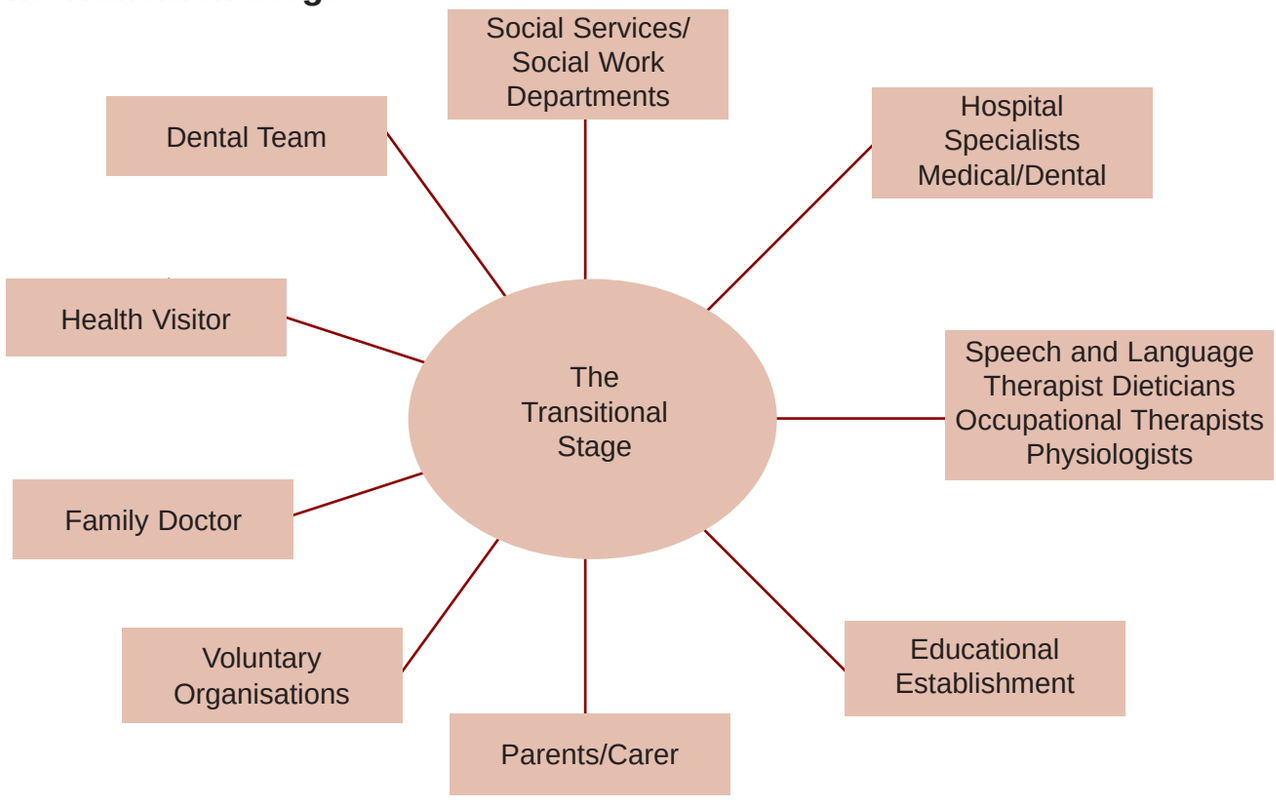


Figure 3. Integrated Care for the Transition Stage

Introduction

This section clearly inter-relates with those for children and adults. This stage is characterised by a period of transition: adolescence to adulthood, parental care to community care or possibly institutional care, changes from schools or educational establishments. Changes in personal development and in self perceptions and relationships with other adults also occur. The issues will be dependent on the individual's degree of learning disability and on levels of social, emotional and financial support. Oral health care needs will be dependent on previous dental disease experience and treatment provided, access to dental treatment, the individual's standard of oral hygiene and dietary sugar intake.

The main emphasis for oral health care should be oral health education and access to professional dental care. The dental professional should establish a clear oral health care management strategy with the person, their parent/carer and any other health care or social services professionals. This may help to ensure that they maintain a functioning dentition without the need for complex or repeated restorative treatment.

Regular Dental Visits

These need to be encouraged and promoted at every opportunity and links established to ease the continuity of care. Parents/carers should be made aware of the role of the Community Dental Service (CDS) as a primary dental care service with the necessary expertise. The decision on whether to choose the General Dental Service (GDS) or CDS should be discussed in training sessions with parents or carers. It is expected that the GDS would refer patients when necessary to the CDS where appropriate expertise exists.

Links Between Dental Services

School leavers, particularly those with mild learning disabilities, may lose contact with dental services especially when these were provided in school. Adults with severe learning disabilities who do not attend day services may not receive the appropriate oral care.
Discharge and referral schemes should be developed to ensure seamless care for those moving from education to work and between services.

Parents' Awareness Days Towards the End of School Life

To highlight the dental services available on leaving school, a written leaflet with contact numbers and details of local dental services may be helpful. Parents need to be made aware of the likely exposure of their children to addictive substances such as tobacco.

3.3 Adults and Older People

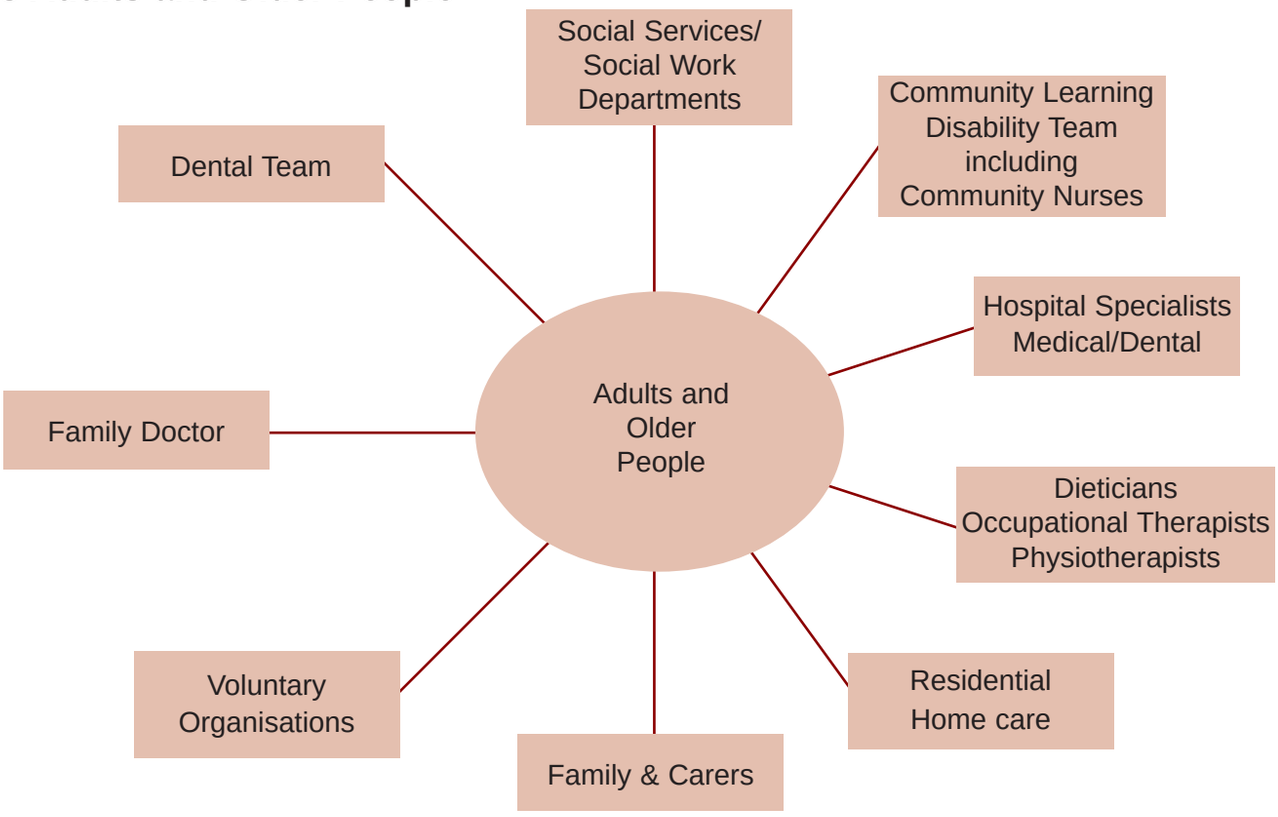


Figure 4. Integrated Care for Adults and Older People

Introduction

Dental disease patterns and oral status of adults in the UK are changing[59]. The general trend is an increase in the retention of natural teeth until later in life[59]. Attitudes are also changing, such that tooth loss is considered less acceptable. The impact of oral conditions on the quality of life of individuals can be profound [7, 118].
People with learning disabilities generally experience the same oral problems as the general population. However, poor oral health is an additional burden and good oral health provides health gain by improving general health, social acceptability, self esteem and quality of life.

Little is known about the oral health of adults with mild learning disabilities since many are not in contact with services. However, studies conducted in day centres and institutions report higher levels of untreated decay and periodontal disease than the general population[39, 41, 47, 119, 120]. A more recent study of adults not in contact with the Community Dental Service (CDS) showed higher levels of untreated dental caries and periodontal problems than both the general population and previous studies where the CDS provided care[121]. High levels of periodontal disease are consistently associated with poor standards of oral hygiene.

Adults with learning disabilities should not be viewed as a homogenous group. Those with mild learning disabilities are more likely to have filled teeth, fewer extractions and more untreated active decay than adults with more severe disabilities[37; 41]. Oral hygiene has been found to be better in those with mild learning disabilities[37] and the poorest oral hygiene has been reported in those with additional disabilities[46; 47] .

Care received appears to be related to the individual's ability to comprehend or co-operate with treatment[39] since a significant number of adults require treatment under general anaesthesia[39;122].

Fewer dentures are provided for people with learning disabilities despite their higher level of extractions and, where dentures are worn, there is a higher prevalence of denture related pathology associated with poor denture hygiene and wearing dentures at night[41].

Health and Social Care Policies

Recent changes in policy in Healthcare and Social Service provision have had profound effects on the services provided for people with learning disabilities. Services for adults have been particularly affected by the policies of Normalisation and Integration (as described by Wolfensberger[22]) and Social Role Valorisation, adopted in the last decades. Oral healthcare has not escaped these influences[123]. People who were resident in long stay hospitals are now living in residential accommodation in their communities as a result of changing national policies. The old style hospital based services are no longer seen as an appropriate form of provision[124; 125].

There has been an increasing emphasis on more flexible approaches to day activities for people with learning disabilities. This has led to changing roles for the adult resource centres, which are no longer seen as the sole provider of day opportunities. Employment, continuing education, and community leisure activities are all more appropriate ways to meet the individual aspirations of people with learning disabilities. This trend has made the provision of oral care increasingly difficult as people move out of institutional care.

The 'New NHS' looks very different from that of the past and its influence is yet to be assessed. There is no doubt that such changes present challenges to service providers, which require new approaches[126].

Diet and Nutrition

The influence of diet and nutrition on oral and general health is an issue, which must be addressed[47, 127]. Dental health is linked to happiness and good general health and there is evidence that aesthetically acceptable and functionally adequate dentitions affect self esteem, confidence and socialisation[128-130]. These are all important issues for people with learning disabilities.

Sugars are not only detrimental to oral health; they also have a negative impact on general health such as diabetes, obesity and coronary artery disease[101]. Thus the reduction of sugar intake for oral health can also benefit general health and dietary advice should be given in the context of healthy eating with appropriate choices made available[131]. The Nutrition Task Force emphasises the importance of providing simple, practical and realistic guidance for selecting a balanced diet[5]. Professional carers of people with learning disabilities will require appropriate training and resources to promote healthy eating policies. Training should include the effect of prescribed oral food supplements to maintain nutritional status for some people with learning disabilities, and sugar based liquid medication, which poses real challenges for dentate individuals[132]. Carers need to be aware of the risk factors for oral health and should be advised on techniques to prevent dental decay, as should other professionals who are involved in prescribing e.g. GPs and dieticians. Policies should be developed, which will advise on referral to the dental team for advice and care.

Oral Health Education and Promotion

Education and training in oral health care on a 'one to one' basis is known to be effective[47]. In those with mild learning disabilities, this may be very appropriate and use of dental hygienists to provide successful training is well documented[47].

All parents and carers working with people with learning disabilities should receive training to support the concept of oral health care. Lack of formal training for professional carers is reported and this is particularly pertinent to those cared for in community-based, residential accommodation[8]. Lack of staff training means that further barriers to care are experienced by people with learning disabilities. This is based on the low priority that oral healthcare has in the minds of many carers[108], together with the lack of personal perception of oral health problems by individuals themselves[133;134].

Presently, guidelines within community homes do not routinely include oral care and little specific staff training is carried out. The training is generally via 'job shadowing' of other staff. Residential Home Managers recognise that there is a need for oral care guidelines and standards and agree that training in good practice would be valuable[135;136] .

There are examples of good practice in some areas of the country in developing oral health care guidelines for people with learning disabilities cared for by professional carers. Good practice should be widely encouraged and disseminated.

Examples of Good Practice

Development and audit of standards established with co-operation of dental team and care staff at long stay hospitals and community group homes. Community Dental Services Gwent HealthCare NHS Trust.

Use of oral assessment by care staff to established a basic need. Community Dental Services Gwent HealthCare NHS Trust.

There is a substantial turnover of staff in residential group homes and in-service training needs to be repeated regularly to ensure that all staff are included. Improvements in oral health have been demonstrated through training of direct care staff[137]. Oral health input to staff induction programmes can overcome some difficulties in releasing staff for training[138].

Oral Assessment and Care Planning

In order to raise the profile of oral care in the assessment/care-planning process, the importance of oral assessment and care should be included in national strategies for people with learning disabilities. Inclusion at this level should ensure translation into local strategies, few of which presently include either professional oral assessment and care, or daily care at home. Following assessment, a written oral care plan facilitates communication between the service user, carers and the dental team and helps to ensure that all those involved in the individual's care are aware of his or her needs. It emphasises the collaborative nature of oral health care based on partnerships between all involved[21].

Treatment and Care

Oral treatment planning and care should be provided using the same basic philosophy and principles as those for the rest of the population[6]. The complexity of treatment provided may be influenced by the severity of the learning disability[37;41;47]. Studies report consistently poor periodontal health associated with poor oral hygiene[41, 47,138], which directly influences prognosis for treatment. It is a universal principle that account must be taken of oral hygiene and periodontal health in developing a realistic treatment plan.

Example of Good Practice

Emergency patients are managed by a questionnaire assessment, which enables a member of the dental team to determine the nature of the emergency and hence arrange for treatment by the appropriate personnel (Audit Project Enfield and Haringey Community Dental Services).

Frequency of professional oral assessment depends on individual need. It may vary from annual checks for edentate patients, to weekly hygienist interventions for those with the poorest oral hygiene. In some cases, assessment may have to be undertaken together with treatment under sedation or general anaesthesia. Frequent acclimatisation visits may avoid the need for general anaesthesia. For those unable to accept clinical assessment or routine dental care, it may be necessary to utilise relative analgesia, oral, transmucosal and intravenous sedation, or general anaesthesia in order to provide acceptable oral health care. These interventions should be discussed and agreed with carers and the multi-disciplinary team as an integral part of the treatment planning process.

Expectations of carers may not equate with the ability of the individual to tolerate the complex process of denture construction or the wearing of dentures. Collaboration and communication are again crucial to the treatment planning process for such individuals.

Uptake of oral care services can be increased using mobile facilities at adult resource centres and in a person's home but should be appropriate to the individual's need.

Consent for Treatment and Care

Treatment and care for adults must take account of the barriers to care experienced by people with learning disabilities (Section 2). Care managers recognise that residents' refusal or inability to accept care are barriers to treatment[61]. Problems arise when people, who are unable to make adequate and informed decisions for themselves, need treatment for which they are unable to provide consent.

The dental professional must work in partnership with carers and clients, since the development of trust is essential to create an understanding of the issues relating to duty of care and responsibility to provide care in the individual's best interest[140]. This will help to avoid unnecessary conflict and delay in providing appropriate care and treatment. An understanding of the law relating to adults who do not have the capacity to consent is an essential requirement for both carers and professionals (Section 5). Protocols, which address the issues of inability to give informed consent in relation to oral hygiene and treatment, must be developed to deal with these difficult moral, ethical and legal situations.

Example of Good Practice

A protocol for the provision of oral care for adults without capacity to give consent has been developed by the Community Dental Services Gwent HealthCare NHS Trust.

Secondary Care Services – Hospital Care

Dental treatment for adults who require treatment under sedation or general anaesthesia is largely provided in hospital with critical care facilities. The latest General Dental Council guidance on the provision of treatment under general anaesthesia will restrict dental general anaesthetics to provision in hospital[115]. There is evidence[1] of long waiting times for people with learning disabilities and it is essential that seamless services, including specialist provision for treatment under sedation or general anaesthesia, are protected and developed for adults requiring this care. This will ensure that there is no discrimination on the basis of their disability. The provision of treatment for those with complex medical conditions will require careful liaision with appropriate medical and dental specialists within the hospital service.

Referral and Discharge Schemes

There is evidence that people with learning disabilities do not seek access to oral care services on their own initiative (Section 2). It is therefore essential to ensure that parents, carers and health professionals have effective referral mechanisms to an appropriate dental service. Mechanisms based on a simple referral form already exist for residents leaving hospital and from health professionals to the Community Dental Service. The effectiveness and benefits of direct referral systems can form the basis for multidisciplinary audit. Effective transition of care requires communication with other health care professionals and carers.

Example of Good Practice

Service users admitted to an assessment unit have an oral health assessment completed on admission and are referred for an oral examination. On discharge, a detailed referral to include medical and dental history, behaviour and management problems, preventive advice, and capacity for consent is made to the Senior Community Dentist who facilitates contact with an appropriate dental service (Department of Adult Dental Health, Cardiff Dental Hospital).

Older People with Learning Disabilities

Older people with learning disabilities may face barriers associated with ageing in addition to the barriers identified in Section 2. They may also suffer from cognitive, mental and medical problems associated with advancing age. The needs of residents in nursing homes, residential and continuing care are addressed by BSDH Guidelines[8] (Web-site www.bsdh.org.uk). Their rights to oral health and appropriate oral care services must not be overlooked.

Services for Adults with Learning Disabilities

Adults with learning disabilities can be considered as follows:

- People with low support needs – are able to lead relatively independent lives and to have only mild learning disabilities.
- People with medium support needs – require assistance with a wide range of every day skills though they are able to undertake a number of tasks for themselves independently. They tend to have moderate to severe learning disabilities.
- People with high support needs – typically require 24-hour care as they are able to carry out only a few if any activities of daily living. They will have profound learning disabilities usually with additional physical and/or sensory difficulties and significant medical problems.

For the purposes of oral health care provision, it is appropriate to look at those with low support needs, and those with medium and high support needs separately, since they have different management requirements.

People with Low Support Needs

Evidence of the oral health needs of adults with mild learning disabilities comes from surveys carried out in adult training centres and similar institutions[37;39;41; 47;119]. The more able, less dependent adults are found to have more fillings, fewer extractions and better oral hygiene. They are also able to obtain care in the General Dental Service more than other attendees at the centres[37]. It is however also evident that this group is not gaining access to general health care services[11] and may be 'slipping through the NHS net', leaving no room for complacency. It is important that people with mild learning disabilities are monitored so that support with home care can be provided when necessary.

During the process of developing the guidelines, people with mild learning disabilities were consulted through consultation groups and questionnaires. Their expectations did not differ from those of the general population in that they felt that their teeth are important, they recognised the importance of good oral hygiene and regular dental check-ups. They wanted to visit the dentist and be cared for by an understanding dental team.

Even those with relatively mild disabilities, who are independent in many aspects of daily life, rely on the help of community nurses and social workers for support. These professionals, as well as carers and parents are crucial to ensure access to good oral care for this group. All people with learning disabilities should have an individual care plan that includes oral health care. The care plan would facilitate the actions necessary to ensure appropriate access to care.

People with Medium and High Support Needs

Many adults with medium and high support needs have always lived at home with their families. A significant number also lived in institutional care and have now successfully moved to community based living in Group Homes with full time employed carers, while a few still reside in long stay hospitals[123]. Many adults with this degree of disability are unable to make their own decisions although most can indicate likes, dislikes and choices.

People with medium and high support needs are generally reliant on others, such as community nurses and community learning disability teams, for their daily care with even the more able relying on support and encouragement within the residential setting. This group presents particular challenges to care providers both in the management of their care and the ethical issues surrounding their sometimes reduced ability to give informed consent.

Generally, the CDS provides the primary oral health care for this group[113], with teams trained to provide appropriate services for those who do not, or have not had, past access to care in the General Dental Service. The CDS should continue to develop services for this group of people.

3.4 Communicating with People who have Learning Disabilities

Background Information

Communication is a two way process involving the receiving and sending of information through a variety of means written, spoken and a host of non-verbal methods such as tone of voice, facial expression, body language and gestures. People with learning disabilities may find the use of pictures, symbols and signing helpful forms of communication.

People with learning disabilities often have difficulties communicating with those around them. They may have specific difficulties understanding and using verbal methods, which may be:

- Due to hearing and visual impairment.
- Difficulty focusing and sustaining their attention on what others are saying.
- Poor auditory memory.
- Very lengthy processing and response time (and others not allowing enough time).
- Difficulty understanding the words used by other people; particularly grammatical concepts such as negatives (e.g. not, don't, isn't, won't etc.) and time concepts (e.g. tomorrow, in a week, in ten minutes etc.).
- Limited expressive vocabulary or word finding difficulties.
- Weak and/or uncoordinated oral musculature.

Preparing the Patient for the Appointment

The health care team needs to know details of their patients' communication skills and use the appropriate language, body posture and eye contact. Every effort should be made to speak to the patient directly using the name they prefer.

Example of Good Practice

Going to the dentist (1999) explaining routine experiences for children and adults with learning disabilities and/or communication problems Makaton Quality Mark Homefirst Community Trust, Ballymena Community Dental Services have produced a very helpful booklet.

3.5 Management of Specific Complications

This section will deal with the management of specific problems.

Drooling

Drooling is essentially the physical escape of saliva from the mouth due to problems with the co-ordinated control mechanisms of oro-facial and palato-lingual musculature. It is seen in people who have physical or learning disabilities and those who have poor neuromuscular co-ordination. It is believed that inadequate swallowing and lip closure and head forward posture are the main causes of drooling[141]. Occasionally, drooling can occur where there is no obvious disability.

Drooling can cause chronic irritation of the facial skin; increase in peri-oral infection, halitosis and dehydration due to fluid loss. Many approaches have been described in the management of drooling but none appear to be universally successful. Non-surgical approaches include:

- Bio-feedback techniques, bio-functional therapy, behavioural therapy and physiotherapy.
- Functional appliances can reduce drooling and improve swallowing and chewing in people with cerebral palsy[141].
- Pharmacological methods can be employed but the side-effects can be more problematic as the drugs do not act solely at the required site[141].

Patches have been used with some success in the past. Surgical methods may not always be successful. Management may be aimed at alleviating symptoms, maintaining the head in an upright position is often the most appropriate method.

The role of the dentist is to diagnose the problem and treat any oral infection promptly. Available treatment options should be discussed with the parents and multidisciplinary team, as the treatment of choice may involve specialist surgery[141].

Bruxism

Bruxism is the non-functional grinding of teeth. It can lead to tooth-wear and in some severe cases, can cause pain and infection. Bruxing can result in exposure of dentine[4; 142]. It is prevalent in people with learning disabilities and there is very little research on the treatment options.
There is no evidence that bruxism can be treated. The provision of bite guards can be helpful to prevent damage but individual assessment is required.

Erosion

Frequent exposure of the teeth to any acidic food or liquid may cause loss of enamel by chemical erosion. Erosion may be a result of intrinsic or extrinsic acid sources.
The intrinsic acidic sources include:

- Gastro-oesophageal reflux[143,144], which may be due to sphincter incompetence, increased gastric pressure and increased gastric volume.
- Vomiting.
- Rumination.

The extrinsic acid sources include:

- Diet through the consumption of soft drinks, alcoholic drinks and citric foods.
- Environmental contact with acids as part of work or leisure activities.
- Medications and oral hygiene products: Vitamin C and Iron preparations are acidic. Some mouthwashes and saliva substitutes are also acidic and can erode teeth[144].

Management of erosion includes:

- Gastro-oesophageal reflux - Consult with the patient's doctor or refer to a Gastro-enterologist if necessary[144].
- Dietary analysis and counselling to reduce the intake of acidic drinks and food.
- Desensitisation through the use of fluoride toothpaste and mouthwashes.
- Restorative treatment can be very complex[145]. The success depends on patient compliance.

Preventive programmes must be the cornerstone of the management of dental erosion.

Dry Mouth

Saliva is an important body fluid, which plays a vital role in protecting the oral mucosa and teeth, as well as facilitating digestion, swallowing and speech. Approximately one quarter of the adult population may suffer from a dry mouth. Patients sometimes feel they have a reduced salivary flow when investigation reveals normal production. The most common cause of change to saliva flow rate is medication or systemic disease. Sufferers are more prone to dental decay, infection of the oral mucosa and periodontal disease and should be seen promptly by a dentist so that preventative measures can be implemented. Use of saliva substitutes is often beneficial.

Self-Injurious Behaviour (SIB)

Oral self-mutilation may be seen in people with learning disabilities and is more common in children[146]. The pain of SIB does not deter further injury[147]. It may be linked to Cerebral Palsy or disorders such as Lesch-Nyhan or Riley Day Syndrome. The oral injuries that are inflicted can lead to permanent damage[148]. Before treatment can be implemented, a full multidisciplinary assessment is required, this is aided by information from the parents and carers on the origin of the behaviour and time-span. A dental cause should be eliminated in SIB.

Management options include:

- Symptomatic relief.
- Reassurance of parents and carers.
- Distraction when SIB is observed.
- Construction of mouth-guards, bite-planes, splints, tongue stents (good patient compliance required).
- Behavioural psychology to modify behaviour.
- Use of sedation.

People with Feeding Difficulties who are Tube Fed

The term tube fed will be used to include feeding by gastrostomy, jejunostomy and naso-gastric tube. People who are tube fed have a number of problems. The reason for tube feeding may include inadequate diet, nutritional need, child failing to thrive and/or impaired swallowing. It has relevance to general health because an inadequately protected airway increases the risk of gastric reflux causing aspiration, which leads to recurrent bouts of pneumonia.

Problems that can occur:

- Dental erosion related to gastro-oesophageal reflux and reduced saliva production.
- Oral hypersensitivity increases the discomfort of the mouth during periods of tooth eruption. Dummies can be used to decrease hypersensitivity. Massaging the child's cheek and stimulating the senses helps the body to prepare for food. Maintaining the ability to chew and swallow is important for people who are likely to return to oral feeding. Advice should be given to carers concerning the use of 'tasters' particularly those containing sugar.

Oral stimulation is necessary to maintain a certain amount of salivary flow without which rampant dental caries, rapid tooth destruction, dryness and cracking of the lips, crusting of the tongue and build up of calculus on the teeth is likely to occur.

People who are tube fed have difficulty in protecting their airways due to lack of co-ordination of swallowing with breathing. The dental team needs to be aware that dental care has to be provided within a number of constraints.

3.6. Use of Sedation for People with Learning Disabilities

Introduction.

The use of sedation in the care of people with learning disabilities is influenced by a number of factors:

- Age and medical condition of the patient.
- The appropriate use of different drugs and techniques either in primary or hospital dental service.
- Cultural acceptance of sedation.
- Behaviour management problems.
- Support from carers.
- Experience and training of the dental team in sedation techniques.

The suggestions outlined below represent a framework for the use of different sedation techniques. These may change depending on new research, and national professional regulations.

Pre-school Child:

Inhalation sedation.

Oral sedation, transmucosal sedation.

School Age, Transitional Stage, Adults and Older People:

Inhalation sedation.

Oral sedation [149].

Transmucosal sedation[150].

Intravenous sedation[17] (only to be used on patients over the age of 12).

Research in the use of sedation techniques is not extensive, particularly in the very young and elderly. Research into the use of appropriate techniques should be developed.
Training in the use of sedation is a General Dental Council priority for undergraduates.

3.7 Use of General Anaesthesia for People with Learning Disabilities

Despite the decline in dental caries incidence in the UK population there continues to be a need for dental treatment under general anaesthesia for a proportion of children and adults with disabilities[44]. Recent recommendations on the delivery of dental treatment under general anaesthesia in hospital[140] will have local resource implications and a marked impact on services.

The management of people with learning disabilities as with all patients must begin with a careful pre-operative assessment at which medical problems are ascertained, drug therapy confirmed and an anaesthetic assessment carried out. This is also an opportunity to explain the procedures to all concerned.

Indications for General Anaesthesia

- Clear inability to co-operate with contraindication of other patient management techniques including sedation.

Pre-assessment

- A full, updated medical history from the patient's doctor or consultant should be obtained.
- A dental history should be updated at the same time.
- Past anaesthetic history should be recorded.
- Provision of clear written and verbal instructions of the planned procedure to the patient, parent or carer in order to allay anxieties.
- Alleviation of anxiety by:
  Pre-medication (consider a pre-medication prior to or on admission).
  Having a familiar team and environment appropriate to individual needs.
  Advising that it may not be necessary to change normal clothing.
  Supporting carers by considering their needs and anxieties.
- Ensuring the correct consent form is completed. For those unable to give consent, this will require a case discussion involving the multi-disciplinary team, the patient's key worker and next of kin.

Nutritional State

The nutritional state of people with learning disabilities varies considerably. Some are under nourished but others are likely to be overweight because of the ease of access to high calorific food and drink.

Anatomical Considerations

Many congenital and developmental disabilities are associated with facial and oral abnormalities. Indeed this may form part of their dental problem. It is important that the airway of the patient is properly assessed by the anaesthetist. A poor dentition could pose an additional problem during induction. The anaesthetist should also be made aware of problems associated with cleft palate and enlarged tongue.

The Anaesthetic

- The anaesthetist will be experienced in caring for people with learning disabilities for dental treatment.
- Discussions will take place between the anaesthetist and the dental team regarding the patient.
- The appropriate number of trained staff will be used at all times.
- Arrangements must be made with ward and day surgery unit staff to make sure they understand the needs of people with learning disabilities.
- If people with learning disabilities are sharing a ward with other patients, appointments need to be carefully arranged to minimise any disruption that might be experienced.

Social Factors in Assessment

- Arrangements for effective and efficient after care should be in place. This will involve key workers organising someone to stay with the patient on discharge.
- The patient and carer should be given full instructions on postoperative care and an emergency contact number.
- The dental team may need to organise transport to and from the treatment site.
- Appropriate manual handling procedures should be followed[151].

Examples of Good Practice

- The key worker shares information on a planned dental general anaesthetic with the family doctor and other carers e.g. the podiatrists. (Bexley CDS, up to 2000; Bromley CDS, St. Georges Hospital, London Dental Department).
- Dental health care professionals in Liverpool are testing a protocol, which will consider having other treatment needs carried out or assessed at the same time as the dental general anaesthetic is being administered.
- Information for carers of people with learning disabilities when referred for dental treatment under general anaesthesia will provide both the patient and carer with details of the assessment visit, treatment visit and discharge arrangements. (Enfield and Haringey Community Dental Services).

Recommendations

The recommendations relate to the preceding relevant paragraph number. Levels of Evidence are graded A-C. The criteria used for grading of the evidence can be found on the fold inside the front cover of this document.

3.1. Oral health Care of the Pre-school and School Age Child

Prevention and Promotion of Oral Health

- The consumption of sugary foods and drinks should be limited to meal times.
- Cariogenic snacks should be avoided between meals[5].
- Collaboration between dentists and dieticians will ensure that appropriate preventive advice is offered
- Sugars should not be added to bottles of infant formula or follow-on formula.
- Sugary drinks should not be given in bottles or feeders, especially at bedtime.
- Infants should not be left to sleep with a bottle containing sugary or acidic drinks, which will lead to dental decay and erosion of tooth enamel[100].
- Prolonged use of feeding bottles should be avoided.
- Fruit flavoured sugar containing drinks should be limited to meal times.
- Parents should be advised that some baby juices are acidic.
- Ensure that, as far as possible, when medicines are given they are sugar-free[102].

Use of Fluoride

- Fluoride toothpaste should be used[6].
- Children over the age of 6 years should be encouraged to use standard (1000ppm) fluoride level toothpaste[99].
- Direct supervision by an adult is advisable[99].
- Parents should be fully involved in the decision to supplement fluoride levels[99].
- The risks and benefits should be carefully explained so that parents can make an informed choice.
- Professionally applied topical fluoride should be biannual[6].

Oral Health Education

- Instruction in oral hygiene and motivation are important.
- The dental team should appreciate the everyday problems encountered by parents who are attempting to implement a good oral health care routine.
- The causes of gingival bleeding should be explained.
- Oral hygiene programmes should include supervised toothbrushing sessions.
- Oral health education should be given to parents and support services.
- Use of chlorhexidine mouthwash or spray over short periods can be beneficial.[153; 154]

Education and Training of Parents, Carers and Professionals

- Parents and professionals need to be aware of the possibility of dental pain.
- A dental opinion should be sought for unexplained changes in a child's behaviour.

Integrated Care for the Pre School and School Age Child

- Information on access to available services should be circulated to parents, carers and health-care professionals.
- Early referral to the dentist should be encouraged from child development teams and consultant paediatricians[107].
- Health care professionals and carers should be advised of the alternative ways in which oral healthcare can be delivered e.g. home visits, mobile dental units, in special schools in addition to a dental practice.
- Professionals should collaborate to identify children with learning disabilities in mainstream and special education centres and refer to the appropriate oral healthcare services[107].

Initial Visit

- An oral health care plan should be agreed with parent/carer/child.

Regular Attendance

- Regular visits and reviews should be established[60] and tailored to individual needs.
- Acclimatisation to dental treatment should be provided.
- Provision of regular monitoring is the key to the prevention of pain and infection.

Oral Health Screening

- Oral health assessment should be included as part of general health assessment.
- Screening programmes should be developed and sustained in special schools and special needs units in mainstream education.
- Local programmes and dental services should be developed that address the demographic and geographic needs of the local population.
- The increased use of mobile dental units in mainstream and special schools should be explored where appropriate.

Fissure Sealants

- Children at risk of dental caries should have fissure sealants applied to permanent teeth[6] soon after eruption.
- Parents should be advised of the need for regular monitoring and maintenance of fissure sealants[6].

Working with Schools

- Oral health education programmes should be established in special schools and units.
- Oral hygiene should be included in the child's Individual Educational Plan.
- Oral hygiene should be included in personal hygiene training.
- Healthy eating policies should be promoted in schools[114].

Oral Care and Treatment Strategies for the School–Age Child:

- A friendly and supportive clinical environment should be provided.
- Continuity of dental personnel and a team approach should be maintained.
- Children should be acclimatised to the clinical environment gradually.
- Each step of any treatment should be explained clearly.
- Disability awareness training including learning disability for the dental team should be available.
- Equal access to dental treatment under sedation and general anaesthesia should be available.
- Access to emergency treatment under general anaesthesia for pain relief should be provided.
- Increased resources for treatment under sedation and general anaesthesia should be made available.
- Home visits should be provided when required.

Orthodontics

- Refer early with comprehensive information.
- Obtain an orthodontic opinion before arranging treatment under a general anaesthetic.
- Treatment plans should take into account child compliance[117].
- Avoid extracting permanent teeth until co-operation and oral hygiene are adequate.

3.2 The Transition Stage

Oral Health Education and Promotion

- Oral health education programmes should be developed that address the needs of individuals and carers (personal or professional).
- Advice should be given on the effects of smoking, abuse of alcohol, general substance abuse, and if appropriate, these issues should be highlighted with carers and parents.

Professional Oral Health Care

- Contact should be maintained with the same dental practitioner wherever possible.
- Preparation for transition should be made one year in advance and introductory visits arranged to the new dentist if appropriate.
- Referral schemes should be developed to enable continuing oral care.
- Everybody should have a clear policy on oral hygiene with established links to local dental services.
- Oral health should be part of the individual healthcare plan.
- Educational institutions should include oral health as part of training or socialisation programmes.

3.3 Adults and Older People

Dietary Advice

- Dietary advice for all people with learning disabilities should be made within the context of healthy eating policies[131].
- Carers and health professionals should be provided with training to promote healthy eating and its effect on oral health[131].
- Policies should be developed to ensure referral to and advice from the dental team to instigate appropriate prevention techniques.

Oral Health Education

- Oral health education should be provided for all and tailored to individual needs.
- All carers (family or professional) providing care or support for individuals unable to care adequately for themselves should be given advice in oral health education[8].
- Oral care to be provided at home for people with learning disabilities should be documented in individual oral care plans.
- Standards for oral care should be part of operational strategies in individual residential homes.

Oral Assessment and Care Planning

- Everyone should have a regular oral assessment.
- The frequency of oral assessment should be related to the individual's needs.
- Carers should be encouraged to obtain an oral health assessment for their client.
- An annual assessment should be carried out for people who are edentate.
- Assessment should be more frequent for those with multiple disabilities, those on sugar-based medication or sugar-based dietary supplements and other risk factors for oral health.
- Oral care should be an integral part of social care planning and should be included in national, local and residence based learning disability strategies[21].

Individual Oral Care Plans

- A written care plan should follow individual assessment.
- Oral care plans should include a record of professional care to be provided by the professional and the daily oral care to be provided at home.
- Oral care plans should be part of Health Care plans.

Treatment and Care

- Treatment and care should be offered based on the needs of the individual[37,41,47].
- Frequency of appointments should be determined by the need for acclimatisation.
- Treatment and care for adults unable to give informed consent should be discussed with family, carers or advocates.
- Protocols for oral care should be developed for adults who are unable to make decisions and give consent for their treatment and care[41,47,138].
- Secondary services and in particular general anaesthesia and sedation services should be available locally.
- Waiting times for treatment should be comparable to those for the general population.
- Emergency care for people with learning disabilities should be available on the same basis as the general population.
- Treatment and care should be provided in an empathetic and knowledgeable environment.
- Oral care and treatment should be provided on a flexible basis dependent on the personal circumstances of the patient e.g. domiciliary care provision and using mobile facilities.

Referral and Discharge

- Effective referral mechanisms should be developed to encourage multidisciplinary referral of people with learning disabilities to oral health care services.
- Effective referral mechanisms should be developed for adults leaving hospital and for those moving between residential homes.

Older People:

- Oral health care services should be similar to those available to the general population.
- Oral care for older people with learning disabilities should take into account the difficulties and barriers posed by both advancing age and learning disability[8].

People with Medium and High Support Needs

- Primary dental care services should continue to be developed for all adults with learning disabilities.
- Services should be provided in general dental practice for those who are more independent.
- Services should be provided in the Community Dental Service for those with higher levels of dependency.
- Health Authorities should include oral health care specifications for people with learning disabilities in Health Improvement Plans.

3.4 Communicating with People who have Learning Disabilities

- The oral healthcare team should know and record details of the patient's preferred method of communicating.
- Appropriate language must be used.
- Speech should be slow and clear.
- The patient should be spoken to directly, using the name they prefer.
- The Oral Health Care Team should be trained in basic signing and communication skills.
- The patient should be given plenty of time to respond.

3.5. Management of Specific Complications

Drooling

- A multi-disciplinary team should make an individual assessment[141].
- Techniques designed to improve posture should be implemented[141].
- Treatment should be started with non-pharmacological and non-surgical methods[141].
- There should be careful monitoring for oral complications if surgical or pharmacological treatment is carried out[140].

Bruxism

- Construction of splints may be helpful but its success is dependent on patient compliance.
- An opinion should be sought from an appropriate dental specialist if required.

Erosion

- Patients should be advised to use fluoride mouthrinses.
- Toothpaste low in abrasion and high in fluoride should be used regularly[144] (not for children below 6 years).
- Professional application of fluoride varnish is advised.[143,144]
- Dentine bonding agents may be of value[143] in the treatment of patients with erosion.
- An opinion should be sought from an appropriate dental specialist if required.

Dry Mouth

- Saliva replacements may be useful.
- The use of sugar-free chewing gum and sugar- free fluids should be advised.
- The mouth should be examined frequently.
- Fluoride rinses should be considered to reduce risk of dental caries.
- An opinion should be sought from an appropriate dental specialist if required.

Self Injurious Behaviour

- All dental causes should be eliminated[148].
- Construction of mouthguards or other oral appliances should be considered.
- Distraction and behavioural psychology is a useful management option.

Feeding Problems

- Individual assessment should be carried out.
- Good oral hygiene should be promoted.
- An intensive regimen should be followed to prevent oral disease.
- Dentist and family doctor should be consulted for advice.

3.6 Use of Sedation for People with Learning Disabilities

- Each person should be assessed individually
- Appropriate facilities should be available[115].
- The dental team should have training in the use of sedation for dentistry.[115].

3.7. Use of General Anaesthesia for People with Learning Disabilities

- The appropriate resources and facilities for general anaesthetics should be available locally to treat people with learning disabilities[115].
- General anaesthesia should be the last choice for treatment[115].
- Collaborative work should be undertaken with professional colleagues to minimise the number of general anaesthetics required.

4
Practical Oral Health Information for Service Users, Parents and Carers

The dental team play an important role in the overall care of the mouth but the day-to-day care provided in the home environment is the key to a healthy mouth. These guidelines are designed to help maintain a good standard of oral hygiene by optimising toothbrushing techniques and overcoming some of the difficulties, which may be encountered during toothbrushing procedures.

4.1. Mouthcare Advice

Toothbrush

Electric toothbrushes are more effective[152] than manual ones and should be used when individuals can accept them. If a manual toothbrush is used, it should have a small head with smooth and rounded tufts. A child's toothbrush is suitable for reaching awkward areas of the mouth in an adult. Whichever method is used, all surfaces must be brushed effectively.

Brush size to use	Age
Toothbrush for infants	0-2years
Small child's toothbrush	Over 2 years
Child's toothbrush	7 years to Adult

Toothpaste

Always use fluoride toothpaste. Non-foaming toothpaste are available (e.g. for people fed by tube or those intolerant of foaming agents).

Chlorhexidine Gel

This is clinically effective in reducing plaque bacteria over short periods. It should be used as recommended by the dentist or hygienist[153; 154].

Denture Care

- Dentures should be removed from the mouth for cleaning.
- Hold the denture over a bowl of water to avoid damage if it is dropped.
- Brush thoroughly using a small, soft brush and unperfumed soap or toothpaste.
- Plastic dentures should be soaked in hypochlorite cleaning solution, (Metal dentures should be soaked In an alkaline peroxide solution) for 30 minutes rinse, brush and rinse again before storing dry overnight [155].
- Dentures should be marked with the person's surname and initial.
- Carers need to assume the same responsibility for denture care whether individuals and/or people in their care have partial or full dentures.

If the person has no natural teeth, it is important that carers clean the oral tissues daily with a soft toothbrush or gauze to remove plaque and so maintain good oral health. Professional carers assisting someone to clean their teeth or mouth should wear latex free gloves.

4.2 Overcoming Specific Problems in Oral Care

Biting on the toothbrush: Allow person to continue biting the toothbrush whilst the teeth are cleaned with another toothbrush.

Aids to toothbrushing: Finger shields have a small head of soft latex tufts and may be useful for some people. Fingerstalls are small so their use is limited to people with small hands. They are less effective than a toothbrush for removing plaque.

Strong tongue thrust: A mobile tongue or tight lip may tend to push the toothbrush out of the mouth, or away from the front teeth. A flannel or gauze-square wrapped around the forefinger to gently retract or hold back the tongue or lip may be used. It will need patience and perseverance.

Gagging or retching on brushing: In order to reduce gagging and retching it may be helpful to start brushing from the back teeth and move forward[156].

Reduction in oral sensitivity: Some children who have disabilities may require a considerable amount of oral de-sensitisation. Various appliances are sometimes suggested by occupational therapists and speech and language therapists for this procedure. However, they do not remove plaque if used for cleansing.

Reduced cooperation: A different area of the mouth can be brushed on different occasions keeping note of the area brushed each time (i.e. several short brushing sessions). Other distractions such as music and videos can be used, and brushing whilst in the bath can be of benefit.

Lack of co-operation: A degree of physical assistance may be required to accomplish satisfactory toothbrushing, such as holding hands or lying a small child back into the lap. The parent or carer may need to take care not to be accidentally bitten. A second person may be required to hold hands to prevent the individual from pulling the toothbrush out of their mouth.

4.3 General Dental Advice for Service Users

Diet

- Keep foods and drinks that have sugar in them to mealtimes.
- Between meals, avoid snacks and drinks that contain sugar are carbonated or fruit flavoured. Choose bread, toast, nan bread, chapatti, poppadums, cheese, fresh fruit and vegetables instead. Drinks could be milk, water, tea or coffee (without sugar) or acknowledged as “tooth kind”.
- Always ask your doctor or chemist for sugar-free medicines.
- Moderation and infrequent consumption of food and drink, which contain sugar is a good regime to follow.

Oral Hygiene

- Brushing teeth and gums helps keep the mouth healthy.
- Clean teeth and gums twice every day – you may need some help to get them really clean.
- Choose a small sized toothbrush – you may find it easier to use an electric toothbrush.
- Use a toothpaste with fluoride.
- If your gums bleed – keep brushing – gently and thoroughly.
- If your gums continue to bleed contact your dentist

Visiting the Dentist

- Visit your dentist at least twice a year.
- Tell the dentist if you are having any trouble with your mouth.
- Find a dentist you can talk to – ask your family or friends.
- You may want someone you know to accompany you to the dentist.
- Tell the dentist about any tablets or medicines that you are taking.

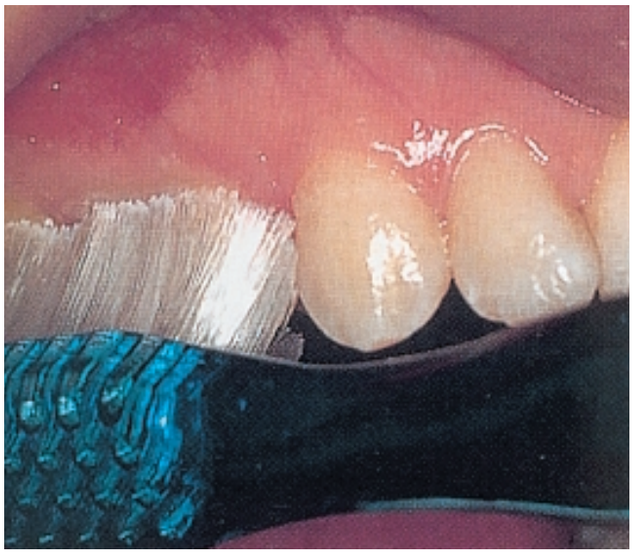
4.4 Practical Advice for Carrying Out or Assisting with Toothbrushing

- Always explain what you are going to do first; brushing someone else's teeth is an invasive procedure and can be frightening.
- Choose a suitable time, when carer and person are relaxed.
- Make sure the person is comfortable (e.g. seated in front of a washbasin, in their wheelchair, or on the bed or floor) and their head is well supported.
- Stand behind the person, slightly to one side, but this position may have to be varied, according to what is comfortable.
- Toothbrushes can be adapted in many ways for those who have limited manual dexterity.
- Gently draw back the lips with thumb and forefinger on one side of the mouth to first gain access to upper teeth. Brush teeth and gums using short scrub motions paying particular attention to gum margins.
- Carry out the same procedure for the rest of the mouth, so that all teeth have been brushed.
- An 'order of brushing' should be decided to ensure no areas are missed, but if co-operation is limited, brush different areas of the mouth each day.
- If possible brush the inner and biting surfaces of all teeth to ensure all plaque and food debris has been removed.
- If teeth are loose, brush them carefully but try to clean them every day.
- Do not stop brushing if you notice gums bleeding; leaving plaque behind on the teeth and gums will only increase gum problems.
- Partial dentures should be removed before cleaning natural teeth.
- If possible gently hold and brush the tongue.
- Encourage the person you are assisting to do as much as they are capable of themselves. Be prepared to prompt, encourage or assist as necessary.
- Help the person to rinse out with water or clean round with a damp swab.
- Straws can be useful to help people rinse their mouth.
- Professional carers should wear latex free gloves for cross infection control when assisting with toothbrushing.
- Gloves should be changed for each individual.
- Use disclosing tablets on the teeth to check the effectiveness of toothbrushing and in removal of plaque.
- Use a chart to record toothbrushing.

If you have any problems, ask the dentist for advice.

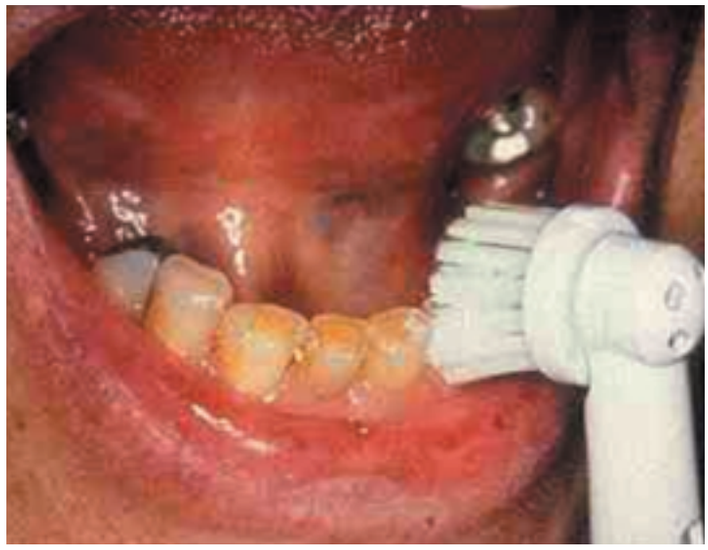
Tooth Brushing

Manual Tooth Brush



Photograph courtesy of Dr Mark Ide

Electric Tooth Brush



Photograph courtesy of Dr Mark Ide

4.5 Oral Assessment

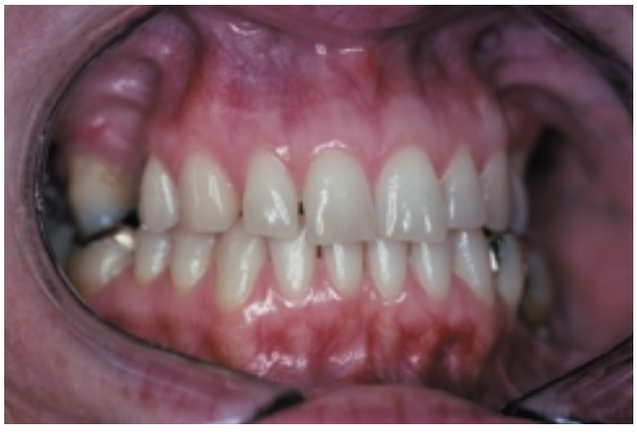
An oral assessment consists of an inspection of the mouth to ascertain the oral health status of the individual. A simple oral assessment may be carried out by carers and is recommended for all people with learning disabilities on admission to residential care, including community group homes.

Example of Good Practice

Development of a protocol for staff to assess residents' oral health status, to act as guidance in reaching ethical decisions and to create a model for residents requiring assistance and support[157].

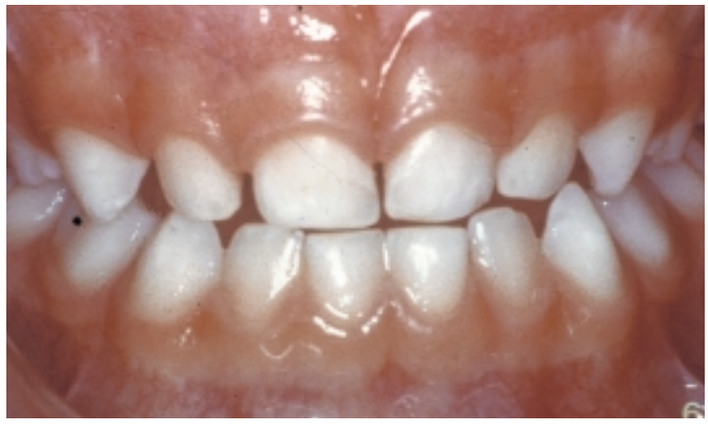
Gums that are healthy are generally firm in texture. They should not bleed on brushing. Pigmentation of the gums is normal in ethnic minority groups.

Adult Healthy Mouth



Photograph courtesy of Dr Mark Ide

Child Healthy Mouth



Photograph courtesy of Mrs Eileen Habbijam

Gums that are inflamed will usually appear swollen and will often bleed on brushing. An oral assessment recorded on a chart is useful for carers to identify any oral problems that might occur e.g. ulcers, soft tissue trauma and any changes. It helps familiarise carers with that person's specific daily oral care needs (including denture care).

More complex assessments involving oral examination require training to recognise signs and symptoms of pathology and need to be carried out by the dentist. It would be useful to have an oral care plan written up following each dental visit.

The oral care plan should include a record of both the professional care to be carried out by the dental team, and the preventive care to be carried out at home. This will help to promote partnership between the people with learning disabilities and the carers and professionals.

Example of Good Practice:

An Oral Health Care Plan

(Community Dental Services Solihull HealthCare NHS Trust)

Name

Problem identified in conjunction with dental staff	Goal	Specific Action Planning specific methods	Materials Required	Staff Informed	Date

I agree to the above programme taking place. . . . . Next Review Date . . . . . .

The person's dentist should be contacted if any changes are noticed in the mouth or if there are any unexplained changes in behaviour. Cancer can occur in the mouth but is treatable if detected early.

Recommendations

- An oral assessment should be recorded on a chart.
- Every person with a learning disability should have an individual oral care plan.
- Carers should seek professional help and advice to carry out daily oral care procedures.
- Individual carers should not make the decision to discontinue oral hygiene practice.
- Trust and good working relationships should be developed.
- The frequency of sugary drinks and snacks should be limited in the diet to mealtimes[5]
- Healthy snacks should be encouraged as an alternative[5].
- Sugar-free medicines should be used whenever possible[5].
- The consumption of fizzy drinks and citrus fruit should be limited to mealtimes[5].
- All people with learning disabilities should be registered with a dentist and attend regularly.
- Carers should provide appropriate levels of support during dental appointments and liaise with the dentist and service user about day-to-day oral care.

5
Commissioning of Oral Health Care Services for People with Learning Disabilities

5.1. Prevention of Dental Disease

Introduction

The prevention of dental disease is the principal aim of oral health promotion and oral health education. The scientific background and recommendations for oral health promotion are contained in the recent policy document published by the British Association for the Study of Community Dentistry in April 2000. This has been adapted for these guidelines.

The policy is divided into, Commissioners and Commissioning of providers. These categories will be used to consider the guidelines for people with learning disabilities.

Commissioners

Creating Supportive Environments
Commissioners should promote oral health by commissioning living and working conditions that are conducive to health and well being. Public Health Departments should work jointly with Social Services Departments through the Health Improvement Plan to ensure good oral health for people with learning disabilities who are residents of homes or otherwise in their care. This can be done by: provision of a healthy diet; oral hygiene facilities and dental services; encouraging oral health in care plans.

Health Authorities/Primary Care Groups (Trusts) must work with water providers to adjust the level of fluoride in the water to the optimum level to reduce dental caries, where this is practical. Whilst the evidence is equivocal on whether people with learning disabilities are at greater risk of dental caries than the general population, there is considerable evidence that they receive less restorative care. Water fluoridation can therefore potentially have a greater benefit for people with learning disabilities.

Building Healthy Public Policies
Commissioners should work with all policy makers, within and beyond the health services, to make healthy choices the easy choices. Health Authorities and Primary Care Groups or Trusts should work with schools and education establishments, employers and care providers for people with learning disabilities to include oral health in the joint Health Improvement Plan.

Schools must include both those dedicated to children with special needs, and those in the mainstream with attached units for special needs children.

Strengthening Community Action
Opportunities presented by Health Action Zones and Healthy Living Centres should be seized by Commissioners and developed with sensitivity for people with learning disabilities.

Developing Personal Skills
Commissioners should support the development of personal, social and political skills, which enable individuals to take action to promote health. Non-dental services should be commissioned e.g. Health Visiting, Practice and Community Nursing, which promote such skills, particularly where they are in contact with people with learning disabilities.

Re-orientating Health Services
Commissioners should promote preventive services for health gain, away from curative and clinical services. This is particularly important for those who are able to receive restorative care only with difficulty. They should utilise an evidence-based approach to invest in proven preventive therapies e.g. use of fluoride, and disinvest in services with evidence of no health gain. Services should be purchased which shift resources, personnel, skills and facilities towards disease prevention in people with learning disabilities.

Provision of Oral Health Promotion Services
Providers of oral health promotion services should use the whole range of health promotion strategies for people with learning disabilities. These include developing healthy policies; creating supportive environments such as the provision of healthy diets; providing oral health education on an individual basis.

- All programmes of oral health promotion for people with learning disabilities should have specific, measurable, appropriate, realistic and time-related objectives (SMART). These objectives should cover both process and outcomes. They may include policy development, improved availability of healthy choices, improvements in oral hygiene skill, or service provision.

- The attainment of all objectives should be regularly audited or evaluated and the results used as a basis for continuous improvement of programmes. A minimum of 10 per cent of the resources available to a programme should be devoted to evaluation[159]. All those involved in the programme should participate in evaluation, including the target group, their carers, providers and commissioners.

- Oral health promotion is multidisciplinary. Those who need to be involved on a local level include the whole primary health care team in contact with people with learning disabilities, especially doctors, health visitors, midwives and pharmacists; those involved in education, especially teachers, governors and advisers.

- Oral health promotion messages for people with learning disabilities should be based on the Scientific Basis of Dental Health Education[159], the COMA reports on dietary sugars, dietary and weaning reference values [101, 160,161] and any local food and nutrition or infant feeding guidelines. Oral health promotion messages should fit into the overall context of their good general health including physical, mental and social well being.

- Those working to promote the oral health of people with learning disabilities should possess appropriate qualifications. Training for such qualifications should be available locally e.g. through the dental nurses training schemes.

5.2. Social Services Involvement with People with Learning Disabilities

Social services involvement with people with learning disabilities is an important and long standing one. With the implementation of Care in the Community, social services became the recognised lead authority in the commissioning and provision of services, either directly or by purchasing from the private and voluntary sectors. There is now a growing trend towards joint working with health authorities as evidenced by Health and Social Care Improvement Programmes (the social care element replacing Community Care Plans) and Joint Investment Programmes. These programmes should address the issue of oral health and plan and resource initiatives to review and improve local services where necessary.

Care home registration and inspection, currently managed by local authority social services, will transfer to a single National Care Standards Commission (and an equivalent within the National Assembly of Wales) under the recently enacted Care Standards Act. The Act (expected to become fully operational from April 2002) will also establish a General Social Care Council and a Care Council For Wales to register social care workers, set standards in social care work and regulate care workers training and education. It is hoped the importance of good oral care will be recognised within the care standards set for care homes and carers.

Recommendations

- Promote oral health care by working with various agencies[159].
- Be involved in the development of joint policies.
- Encourage development of personal skills to promote health.
- Facilitate programmes in prevention for health gain.
- Social Services/Social Work Departments should lead the way in care and support[24].
- Encourage Health care professionals to provide support and help meet health care needs[161].
- Enable Community Learning Disability Teams to help with access to dental care[24].
- Encourage Community Learning Disability Teams to include representatives from the dental profession.
- Commissioners should encourage Health Improvement Programmes and Joint Investment Plans should ensure joint collaboration between Health Authorities and Social Services/Social Work Departments.
- Commissioners should encourage Joint Investment Plans that ensure the development of services include oral health.

6
Education and Training

6.1 Training for Dentists

Undergraduate Teaching Component

There is a conflict throughout undergraduate teaching between the needs of the patient and the involvement of that patient in the teaching process. This is particularly true for people with learning disabilities, for whom health care in a teaching environment may not always be satisfactory. Whilst the development of facilities geared towards people with learning disabilities may be a very desirable development, caution should be exercised to ensure that the undergraduate does not regard such care as divorced from routine general dental practice. It may be more appropriate, wherever possible, to treat people with learning disabilities within the simulated general dental practice environment in a dental school. Thus they can receive their care within an appropriate environment, whilst achieving the aim of normalisation within society[79] to the benefit of both the patient and the dental student. Secondments to local Community Dental Services also enhance this process by, seeing and caring for patients in a community setting.

Postgraduate Education

All dental professionals should undergo continuing professional development to ensure that they keep up to date. Postgraduate education includes both formal courses and informal self-directed learning. It may include education for a purpose, e.g. for a further qualification for promotion, part of career progression, or as part of life-long learning.

6.2 Training for Professionals Complementary to Dentistry (PCD)

The implementation of statutory registration for dental nurses means that future employment will be predicated on formal training and qualification. A basic understanding of the problems faced by people with learning disabilities and their carers is essential in this training. Post-qualification training is available in helping to manage patients under sedation, general anaesthesia and in special care dentistry.

Although the management of patients with special needs is required in the dental hygienist's and dental therapist's curricula, there are few post qualification courses on special care dentistry. Although short courses and conferences are held attendance may have to be self funded. Whilst continuing education is encouraged by the GDC it is not yet mandatory.

6.3 Training for Carers and Other Health Professionals

All health care personnel should receive additional training to support the concept of primary oral health care [162]. Attitudes and value systems of carers also need to be addressed, as training alone is not sufficient to promote behaviour change. Recommendations concerning oral health care have been incorporated into a comprehensive approach to oral health education in Project 2000 which can be adapted for continuing education, post-basic nurse training, and health care workers. Training should also be provided through National Vocational Qualifications. There is an urgent need to expand and develop high quality training in oral health promotion directed at the whole population, the principles of which will apply to those with learning disabilities.

There is a lack of formal training for professional carers. Training programmes based on scientific principles, which stress that poor standards of oral hygiene can be a health risk for some patients should be established for professional carers. This may be established as part of staff induction programmes which can overcome some of the difficulties of releasing staff for training[8] and reinforced during in-service training. It has been demonstrated that training care staff in basic oral health care procedures can help to improve their clients' oral health[158; 162]. Training can be provided through National Vocational Qualifications.

Recommendations

6.1 Training for dentists

Undergraduate Teaching Component

- Ethics and jurisprudence[163] relating to understanding the position of people with learning disabilities should be taught as components of the course to further the understanding of the student.
- The teaching of verbal and non-verbal communication techniques should be included as part of the course.
- Emphasis should be placed on valuing the individual and the avoidance of stereotyping, which is accomplished through the inclusion of disability awareness, behavioural sciences and special care dentistry.

Postgraduate Education

- Formal postgraduate courses leading to a recognised qualification should be actively promoted.
- Postgraduate Deans and commissioners of postgraduate education should be encouraged to fund courses in conjunction with the Adviser in Community Dentistry in each region.
- The care of people with learning disabilities should be an essential component of general professional training for dentists. Experience in General, Community and Hospital Service posts should be arranged to consolidate their professional development.

6.2 Training for Professionals Complementary to Dentistry (PCD)

- Post qualification training should be developed in special care dentistry.
- Integrated study days should be developed with other health care professionals.
- Professional continuing education should become mandatory.
- Courses need to be available nation wide.
- Courses should be developed which will enable PCDs to provide training to groups of health professionals and carers.
- Collaborative study days should be available locally and nationally, where information can be exchanged with colleagues from other disciplines.

6.3 Training for Carers and other Health Care Professionals

- Oral health should be included within the undergraduate curriculum for medical students.
- Formal and informal training in oral care should be provided for all carers and healthcare professionals such as dieticians, occupational therapists etc.
- Oral health should be a core subject in the nursing curriculum for Project 2000.
- Joint Investment Plans should make resources available.

7
Consent to Treatment and Physical Intervention

Introduction

Under normal circumstances, the rights of individuals in Western democracies are specified by law, or enshrined in a National Constitution. In the United Kingdom, in the absence of a written constitution, the rule is generally that a child under 16 may not give consent to their own treatment without the agreement of his or her parents. Conversely, parents can give consent for their children, except in certain circumstances where the views of the child are taken into account. The basis of this is to do with the concept of a person being able at 16 to understand the consequences of the treatment and their acceptance of it[164].

The implication of this view is that no person may give consent to treatment (nor withhold it) for another person aged 16 and over.

These rules do not take into account the position of a person over 16 with learning disabilities who may or may not be able to understand and give consent to dental treatment. Certain guidelines have emerged through Government directives[165], Medical Protection Society advice, and court rulings as precedents [166;167]. The court rulings have not involved dentistry, however, and are mainly related to sterilisation operations. The rulings do apply to people with learning disabilities who require dental treatment.

Children Under the Age of 16

The law in the UK[168] gives power to the parents of a child to consent to dental care, whether the child has learning disabilities or not. This includes the power to consent to a general anaesthetic, which is usually the most risk-prone procedure in dentistry. Where a child is resistant to dental treatment, and requires physical intervention, it is essential the correct procedure is properly followed. The important consideration here is that the consenting parent must fully understand the procedure to which they are consenting. Where there is no parent, or the parent for whatever reason cannot consent, it is possible for a court to give that consent. Thus, the responsibility for consent to treatment can be ascertained for a child under 16. The ability and understanding of the proposed treatment by the child has to be taken into consideration before proceeding with the treatment particularly from 13 and 14 year olds[168]. At 16, for medical and dental reasons, the giving of consent by the child is equated to that given by adults, and thus is legal.

There are other provisions, which apply, such as treating the child in a child-friendly environment by staff properly qualified to provide such care, which are common to all children irrespective of their disability.

Adults Aged 16 or Over

The present position in the UK[139] (except Scotland) is that no person can consent to the treatment of another adult aged 16 or over, even if they are the parent of that adult.

In addition, for consent to be valid, the adult who consents to their own treatment must be able to demonstrate an understanding of the procedure to which they have consented. There must be an absence of extraneous pressures or coercion, for whatever reason. For patients with learning disabilities, information should be presented verbally in a manner appropriate to their understanding[169]. This includes explanations and consent for screening as well as dental treatment. It can be seen that this presents a problem for the dentist wishing to provide care for a person with severe learning disabilities. The situation is not made easier when that patient is in pain.

The Department of Health for England has described a procedure based on the concept of reasonableness [167]. This requires the operating dentist to have the treatment plan agreed with another appropriate dentist or doctor. The operating dentist must demonstrate that their proposed treatment is reasonable, and in the best interests of the patient. Although such an agreement does not constitute consent in the formal sense, it is essential to follow such a procedure.

Example of Good Practice

Two procedures which determine the ability of the patient to give consent. The procedures are laid out as flow charts which give options to follow to arrive at a decision to proceed with treatment with the correct consent. Procedures adopted by Enfield and Haringey Community Dental Services.

In Scotland, it is the medical practitioner who is primarily responsible for treatment and who must decide if the adult is incapable of making a medical decision. This practitioner can authorise treatment to be administered by a third party (e.g. nurses and dentists). A formal certificate, renewable annually, is required from the patient's medical practitioner[170]. (To be implemented in April 2001).

Physical Intervention

The use of physical intervention before or during dental treatment is subject to the same rule of "reasonableness". In an adult who could be assumed to have full knowledge and understanding of the procedure, such physical intervention would be viewed as acting without consent. However, in an adult with learning disabilities it may be necessary to use firm support of the patient, particularly for one with uncontrolled movement, during operative care with sharp instruments. In such instances, it is advisable to utilise the assistance of a carer or relative in such support. This may deflect any thoughts of undue physical intervention. Recording of such precautions is essential.

The principles of protecting both patient safety and their dignity must be the over-riding ones.

Pharmaceutical Intervention

The dentist must consider, in the interests of patient safety, whether the treatment would be more effectively and safely completed under sedation, or even general anaesthesia. The provision of oral sedation should be undertaken following consultation with the patient's medical practitioner.

Recommendations

- In all aspects of care the 'duty of care' of the professional and the 'best interest' of the patient will be taken into consideration[165].
- Seek formal assent for under 16 year olds from legal parent or guardian[168].
- For adults who consent, ensure that they understand the procedure[169].
- For adults without the capacity to give formal consent or who cannot understand, the dentist must act in the patient's best interest and seek professional agreement.
- If physical or pharmaceutical intervention is required, act with openness (and record it), seeking help from the carers.
- Act in the best interest of the patient, taking into account their safety and dignity at all times[165].
- There should be separate forms for adults who cannot consent to be used by the service provider.
- Health care professionals should keep up-to-date with current and developing legislation in this area.

8
Role of Voluntary Organisations

Throughout the UK, there are a number of voluntary sector agencies concerned with learning disability. Collectively and individually, they are an invaluable source of knowledge and expertise on all aspects of learning disability. The voluntary sector has an important role to play in ensuring that the Clinical Guidelines and Integrated Care Pathways of Oral Care for People with Learning Disabilities are not only disseminated but are also implemented. Additionally, these agencies can help by raising the profile of the importance of good oral health care programmes with their members and service providers. They can contribute to training initiatives for the dental team, undergraduate and postgraduate courses and training for staff in service settings.

The learning disability voluntary sector consists of large national organisations, small local groups, associations concerned with rare or specific syndromes, and those representing ethnic minority communities. One of the most significant developments is the independent advocacy service, which provide impartial support for individuals with learning disabilities. They will include:

- Self-advocacy groups, in which people with learning disabilities come together to find strength in unity, explore common problems and share solutions.
- Independent citizen advocacy groups working in partnership with people with learning disabilities to inform them of their rights, help them assert those rights, and extend rights.
- Parent and carer groups in which the members learn from each other's successes, and secure greater success and a diminished sense of isolation by working together.
- Policy-shifting organisations, which advise, campaign, inform and co-operate with others to change national and local policies and practices.
- Service providing organisations, which provide innovative and mainstream services, usually under contract from the statutory agencies, and sometimes with added value from voluntary input.

The bigger organisations produce specific information material. Mencap has a basic oral care leaflet in a number of ethnic minority languages; it also produces training material dealing with oral care and diet for use with parents of people with profound and multiple disabilities. Profound and Multiple Impairment Service in Scotland, has also developed training programmes on dental care and oral health specifically for people with profound and multiple learning disabilities.

There are a number of consortia of voluntary sector agencies and associations of special interest groups, all of which can provide information for their respective constituent members and help with the dissemination of information. Most of the organisations listed will also be a member of one or more of the consortia.

A list of some of the main voluntary bodies in the learning disability field and the umbrella groups, together with addresses and contact numbers is given in Section 10.

Recommendations

Voluntary Organisations should:

- Use their networking and organisational skills to promote oral health.
- Apply political pressure to ensure equitable access to oral health care under the terms of the Disability Discrimination Act[76].
- Promote standards for oral health in residential and support care facilities.
- Collaborate with dental services to provide information appropriate to service user.

9
Further Research

Research and Development/Audit and Academic Services

Oral health promotion policy and practice should be based upon high quality and appropriate research. It is therefore essential that researchers, oral health promotion providers and commissioners work together on a range of research issues relevant to the further development of oral health promotion. This is particularly true for people with learning disabilities, where oral health may be provided for them by a variety of care workers throughout their life.

Areas of further research should include the following:

Pre-school and School Children

- Early identification and involvement of the multi-disciplinary team.
- Determinants of oral health by examining the effect of different types of disabilities on oral health.
- Epidemiological studies nationwide to determine the prevalence of dental disease among populations with disabilities.
- Oral health status and service usage of children attending special units at mainstream schools.

Transition Stage

- Needs assessment on the oral health status of this age group should be carried out and compared to the general population.
- Effectiveness of transfer of oral healthcare.
- Service provision and the resource implications.

Adults and Older People

- Determinants of oral health of people with mild to moderate learning disabilities who do not appear to be in contact with any services.
- Assessment of the oral health status and use of services by older people with learning disabilities.

Quality of Life

- Development of evaluation measures and methods on the various dimensions used in the quality of life issues.

Sedation and General Anaesthesia

- Research into the administration of sedation techniques particularly for children and older people
- Research into areas of alternative medicine, which could help with sedation and relaxation techniques that, will assist in the delivery of treatment.

Training and Education

- Research into methods of training and education.
- Methods to include oral health care in the training process of all those involved in the provision of care for people with learning disabilities.

Feasible Models of Service Delivery

- Policy development to take into account of target groups; structure of service and the personnel involved.

Interventions Available

- Effectiveness of care.
- Overall impact.
- Alternative forms of care focusing on prevention and treatment.

10
Resources

Information on Organisations, Books, Teaching Programmes and Videos

Lack of space in these guidelines prevents recognition of all organisations and resources. The necessary network will be established by the organisations mentioned.

Organisations

Association for Residential Care, ARC House, Marsden Street, Chesterfield, Derbyshire S40 1JY
Tel: 01246 555043 e-mail: arc@binternet.com

British Dental Association, 64, Wimpole Street, London W1G 8YS
Tel: 0207 935 0875 e-mail: enquiries@bda-dentistry.org.uk

British Dental Health Foundation, Eastlands Court, St Peter's Road, Rugby, Warwickshire, CV21 3QP

British Institute of Learning Disabilities Wolverhampton Road, Kidderminster Worcestershire, DY10 3PP
Tel: 01562 850251 Fax: 01562 851970 e-mail: bild@bild.demon.co.uk Website: www.bild.org.uk

British Society for Disability and Oral Health, Dr Janice Fiske, Hon Secretary BSDH, Floor 26, Guy's Tower, Guy's Hospital, London SE1 9RT Tel. 020 7955 3407 e-mail janice.fiske@kcl.ac.uk Website: www.bsdh.org.uk.

Capability Scotland 22 Corstorphine Road Edinburgh EH12 6AD Tel: 0131 346 7864

Down's Syndrome Association 155 Mitcham Road London SW17 9PG Tel: 020 8682 4001
e-mail: info@downs-symdrome.org.uk Website: www.downs-syndrome.org.uk

Down's Syndrome Association of Scotland 158-160 Balgreen Road Edinburgh EH11 3AY Tel 0131 313 4285

ENABLE 6th Floor, 7 Buchanan Street, Glasgow, G1 3HL Tel: 0141 226 4541 e-mail: enable@enable.org.uk

General Dental Council, 37 Wimpole Street, London W1M 8DQ Tel: 020 7887 3800 Fax: 020 7487 2643
e-mail: information@gdc-uk.org Website: www.gdc-uk.org

LEAD c/o Mencap in Northern Ireland, Segal House, 4 Annadale Avenue, Belfast BT7 3JH Tel: 02890 691351

Learning Disability Alliance Scotland c/o The Action Group Norton Park Centre, 57 Albion Road Edinburgh EH7 5QY
Tel: 0131 475 2315 Fax: 0131 475 3316

Mencap Royal Society for Mentally Handicapped Children & Adults, Mencap National Centre
123 Golden Lane, London EC1Y ORT Tel: 0207 454 0454

National Autistic Society of Scotland Hilton House, Alloa Business Park, Whins Road, Alloa FK10 3SA
Tel: 01259 720 044 Fax: 01259 720 051

National Development Team, St Peter's Court, 8 Trumpet Street, Manchester M1 5LW Tel: 0161 2287055

Norah Fry Research Centre 3 Priory Road, Bristol BS8 1TX Tel: 0117 923 8137 Fax: 0117 946 6553

PAMIS (Profound and Multiple Impairment Service) White Top Research Unit, Frankland Building, The University Dundee DD1 4HN Tel: 01382 345154 e-mail: pamis@dundee.ac.uk Website: www.dundee.ac.uk/pamis/

People First Instrument House, 207-215 King's Cross Road, London WC1X 9DB Tel: 0207 713 6400

RESCARE The National Society for Mentally Handicapped People in Residential Care, Rayner House, 23 Higher Hillgate, Stockport, Cheshire SK1 3ER Tel: 0161 474 7323 Fax: 0161 480 3668
e-mail: office@rescare.org.uk Website: www.rescare.org.uk

SCOPE CP Helpline PO Box 833, Milton Keynes, MK12 5NY Tel: 0808 800 3333
e-mail: cphelpline@scope.org.uk Website: www.scope.org.uk/

Standing Conference of Voluntary Organisations Glynhenllan, Carmel Cross Hands Wales Tel: 01269 842601

SENSE National Deaf, Blind and Rubella Association 11-13 Clifton Terrace, Finsbury Park, London N4 3SR
Tel: 020 7272 7774

The Foundation for People with Learning Disabilities 20/21 Cornwall Terrace, London NW1 4QL
Tel: 020 7535 7400 e-mail: mhf@mentalhealth.org.uk

The National Autistic Society 393 City Road, London EC1V 1NG Tel: 020 7833 2299
e-mail: nas@nas.org.uk Website: www.oneworld.org/autism_uk/

Welsh Centre for Learning Disabilities Meridian Court, North Road, Cardiff CF4 3BL Tel: 02920 691795

Books

The Healthy Way – booklet with pictures about visiting the dentist for people with a learning disability British Institute of Learning Disabilities, (See organisation for details)

Catalogue of Dental Health Education Resources for England, Wales and Northern Ireland. Anthony Blinkhorn, Philip J Holloway and Margaret Ashton [3rd Ed] 2000, Eden Bianca Press

Disability Rights Handbook 25th Edition London: Disability Alliance Educational and Research Association 2000, HMSO London

The 'OK' Health Check ref. ISBN 0-9530011-0-5 Published and distributed by: Fairfield Publications, P.O. Box 310 Preston Central, PR1 9GH Tel: 07867 594135 e-mail: fairfield.publications@btinternet.com

"Dental Care for your child". Great Ormond Street Hospital for Children NHS Trust and the Institute of Child Health Great Ormond Street, London WC1N 3JH Tel: O207 405 9200

Going to the dentist (1999) explaining routine experiences for children and adults with learning disabilities and/or communication problems. Makaton Quality Mark Homefirst Community Trust, Ballymena Community Dental Services Spruce House, Braid Valley Site, Cushendall Road, Ballymena BT43 6HL Tel: 01266 635213

'Dental Health-Advice healthy smiles for all for people who may need special help'. MENCAP 1999 available in an expanded English text and in short form in English, Bengali, Gujurati Hindi Punjabi, Urdu (See organisation for details)

Diet and Dental Health Mencap London. (See organisation for details)

Looking after your teeth. BILD Publications. Wolverhampton Rod, Kidderminster, Worcester DY10 3PP Tel: 01562 850251 Fax: 01562 851970

Leaflets

Shaw-Champion Teaching Makaton to Chloe 1997. Down's Syndrome Association, 155 Mitcham Road, London SW17 9PG Tel: 020 8682 4001 e-mail: info@downs-syndrome.org.uk Website: www.downs-syndrome.org.uk/

Leaflet: Speech and language therapy for children with a learning disability' MENCAP, Mencap Royal Society for Mentally Handicapped Children & Adults, Mencap National Centre, 123 Golden Lane, London EC1Y ORT Tel: 0207 454 0454

Learn with Bristles a leaflet for children- how to have healthy, happy, teeth'.
Dental Health A leaflet for parents' Leaflets on dental care - 25p each National Society for Phenylketonuria (UK) Limited (pku), T. Copland, 36 Swanston View, Edinburgh EH10 7DQ Tel: 0131 4454514 (13 /12/99)

The Home and away oral care pack North Warwickshire Community Dental Service, 73 Barbridge Road, Nuneaton, Warwickshire CV12 9PD Tel: 02476 640115

Scope Advisory and Assessment Service More about Drooling Dr PL Pimm PhD with expert advice from Lisl Levett and Dr CW Williams SCOPE CP, PO Box 833, Milton Keynes, MK12 5NY Tel: 0808 800 3333.
e-mail: cphelpline@scope.org.uk Website: www.scope.org.uk/

Teaching Programmes

Mouthcare for residents in homes and hospitals This package is a teaching programme designed for training carers in the workplace and students undergoing assessment for National Vocational Qualification Produced by Cornwall Healthcare Trust, Community Dental Service, Helen Anderson EDT. Janet Dutton EDT. & Joy Glasson EDT. copyright 1997

The Scientific Basis of Dental Health Education: A Policy Document 4th Ed London: Levine RS Health Education Authority 2000

Smiles for All Dental Health education programme for people with learning difficulties. Webb K (1992) North East Warwickshire Health Promotion Service, North Warwickshire Community Dental Service, 73 Barbridge Road, Nunaeton, Warwickshire CV12 9PD Tel: 02476640115

Videos

An unrelated problem
One more problem?
Cornwall Healthcare Trust, Personal Dental Service, The Leats, Truro TR1 3AG Tel: 01872 354318 Fax: 01872 354349

Teeth For Life
Who Cares?
Pretty Clever Pictures
Shepperton Studios, Shepperton, Middlesex TW17 OQD Tel: 01932 572455 Fax: 01932 572047/572195
e-mail: i-hp-p@usa.net

11
Glossary

Acclimatisation	A gentle programmed introduction to operative dentistry
Bruxism	Habitual grinding or clenching of the teeth
Cariogenic Diet	A diet that is high in sugar frequency that promotes tooth decay
Commissioners of Healthcare	People in authority who make sure certain health services are provided for the general public
Cross-bite	A form of malocclusion caused by an abnormality of the lateral relationship of the jaws to each other
Cervical decalcification	Loss or removal of the calcified tissue from the neck of the tooth
Decalcification	Loss or removal of the calcium salts in calcified tissue
Dental caries	Tooth decay
Dentine	The mineralised organic tissue forming the body of the tooth
Edentate	Having no teeth
Epidemiology	The study of the distribution and aetiology of disease
Extrinsic	Having its origin outside and separate from a body, organ or part
Gastro-oesophageal reflux	A condition in which the stomach contents flow backwards into the oesophagus
Gastrostomy	A Surgically created outlet of the stomach on to the skin surface of the abdomen
Gingival hyperplasia	Swelling of the gums associated with gingival disease
Gingivitis	Inflammation of the gums
Halitosis	Unpleasant smelling breath
Imbrication	Crowding of teeth within the same arch
Incisor	A front tooth
Integrated care	Patient focused care involving multidisciplinary working
Intrinsic	Situated within, or relating solely to one part
Jejunostomy	Surgical operation in which the jejunum is brought through the abdominal wall and opened
Naso-gastric tube	A tube passed through the nose into the stomach
Normalisation	The process by which people with learning disabilities are treated the same as the general population.
Opacities	Opaque discolouration in tooth enamel
Oro-facial	In the region of the mouth and face
Periodontal disease	Disease of the gums and supporting tissues of the teeth
Periodontitis	Inflammation of the periodontal tissues which results in destruction of the gums and supporting tissues of the teeth
Peri-oral	Around the mouth
Personal Dental Services	New way of delivering NHS dentistry which involves Dentist, NHS Trust and Health Authorities working together within the National Health Service (Primary Care) Act 1997
Plaque	A layer of bacteria and their products and debris which forms on tooth surfaces
Prevalence	The number of cases of a disease at any given time in any given place.
Primary teeth	The first teeth to erupt in a child's mouth
Project 2000	Initiative to examine and make recommendations concerning undergraduate and pre-registration education of doctors, nurses and therapists complimentary to medicine
Rumination	Regurgitation of food
Tooth morphology	Shape and structure of the tooth

General Dental Service (GDS): Practitioners in the GDS work as independent contractors to the National Health Service, in the main providing treatment on a fee per item of service basis or under separate private contract directly with the patient. The dentists provide care for children and adults, including people with learning disabilities. Some may provide a home visit for a dental examination if there is a problem with mobility. Always check about wheelchair access when contacting a practitioner in the GDS. Lists of practitioners are available from the local Health Authority or NHS Direct.

Community Dental Service (CDS): Practitioners in the Community Dental Service are normally based in local health centres as part of a Community or Primary Care NHS Trust. They provide care for children and adults who have difficulty gaining access to care in the General Dental Service. This includes people with learning disabilities and those with mobility problems. Normally there is good wheelchair access, but it is important to check this. The service contributes to oral health promotion locally and to the dental screening of school children. CDS staff receive relevant additional training to enable them to provide this service.

Hospital Dental Service (HDS): Practitioners in the Hospital Dental Service work in Dental Teaching Hospitals and District General Hospitals as part of a Community or Acute Hospital NHS Trust. They provide specialist care for children and adults following referral, mainly from the CDS or GDS, or local medical practitioners. Care is provided in a range of Consultant led specialities contributing to patient treatment as out-patients, for day stay care or whenever an overnight stay is required. Practitioners in the Hospital Dental Service work closely with their colleagues in the GDS and CDS contributing to seamless patient care.

Members of the Dental Team: Dentist, Dental Nurse, Dental Hygienist, Dental Therapist, Dental Technician, Dental Receptionist, Practice Manager, Oral Health Educator.

Portage Team: Home based teaching programme for pre-school children with special needs provided by the Local Education Authority. It aims to help parents to encourage their children's development by teaching appropriate skills.

12
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Clinical Guidelines & Integrated Care Pathways for the Oral Health Care of People with Learning Disabilities 2001

BSDH

Unlocking Barriers to Care
British Society for Disability and Oral Health

Faculty of Dental Surgery
The Royal College of Surgeons of England

Diana

THE WORK CONTINUES
Funded By: Diana Princess of Wales Memorial Fund
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Comments from Service Users

"I like having my teeth counted and when I clean my teeth well I get a sticker."

"The dentist and nurses are very nice and are always happy to see me."

"It is good fun to know your dentist."

"He tells me how good I am at keeping my teeth clean and that makes me feel very happy".

"He doesn't make me feel afraid."

"The dentist talks to me."

"My teeth were very crooked and after wearing a fixed brace they are now nice and straight."

The orthodontist was very helpful and gave me lots of advice over 2 years."

"I listen to her music."

"They are very friendly and discuss my treatment with me and my mum."

"They are very important for chewing food - also so you can smile."

"I like to have my own teeth so I don't have to take them out."

"Your appearance, to have a nice smile, to eat, and to talk, kissing."

"For playing my clarinet, to eat well and to look really pretty."

"Our teeth make a difference to our appearance."

"Nice teeth make me look good."

"I don't think I could wear false teeth."

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THE PROCESS OF NATIONAL CLINICAL GUIDELINE PRODUCTION

In 1994 the Department of Health requested the Royal College of surgeons to produce National Clinical Guidelines. The Faculty of Dental surgery delegated this task to the respective Clinical Audit Committees in each of the Dental disciplines of:-

ORAL AND MAXILLOFACIAL SURGERY
ORTHODONTICS
PAEDIATRIC DENTISTRY
RESTORATIVE DENTISTRY
DENTAL PUBLIC HEALTH

Draft authors were asked to review the scientific literature on selected topics and produce a draft guideline which was then circulated to an "Expert Panel" for comment and opinion. Expert panels varied according to the subject of the guideline and consisted of individuals who were identified as having a particular expertise in that subject.

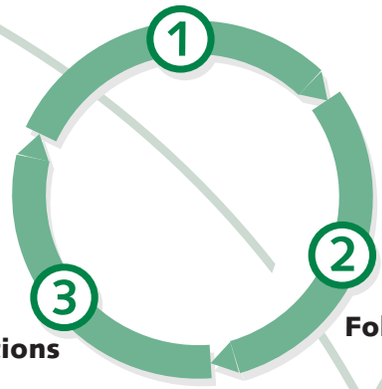
A final Guideline was eventually produced which was assessed, according to the Scottish Intercollegiate Guideline Network (SIGN) classification, as to whether it was based on proven scientific evidence or currently accepted good clinical practice with limited scientific evidence, (See table below).

Levels of Evidence

Level	Type of evidence
Ia	Evidence obtained from meta-analysis or randomised control trials
Ib	Evidence from at least one randomised control trial
IIa	Evidence obtained from at least one well designed control study without randomisation
IIb	Evidence obtained from at least one other type of well designed quasi-experimental study
III	Evidence obtained from well designed non-experimental descriptive studies, such as comparative studies, correlation studies and case control studies
IV	Evidence from expert committee reports or opinions and/or clinical experience of respected authorities

Grading of Recommendations

Grade		Recommendations
A	(Evidence levels Ia, Ib)	Requires at least one randomised controlled trial as part of the body of the literature of overall good quality and consistency addressing the specific recommendations
B	(Evidence levels IIa, IIb, III)	Requires availability of well conducted clinical studies but no randomised clinical trials on the topic of recommendation
C	(Evidence level IV)	Requires evidence from expert committee reports or opinions and/or clinical experience of respected authorities. Indicates abscence of directly applicable studies of good quality.



Where applicable each guideline consists of three broad sections. The first section is a series of recommendations for diagnosis and management. Each recommendation is graded according to the SIGN classification and is clearly marked in the margin - A, B or C.

The second section contains explanatory notes relating to the evolution of these recommendations.

The third section contains references and comments to assist further research into the subject.

It should be understood that a Clinical Guideline is intended to assist the clinician in the management of patients in an effective and efficient way. It is not intended to restrict clinical freedom in the management of an individual case.

gement

Explanatory notes

Discussion and References