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

2012

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 Recommendation

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 absence of directly applicable studies of good quality.

Additional Clinical Considerations & References

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.

Follow up Management

Diagnosis and Management

Additional Clinical Consideration and References

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

Reviewed and Updated 2012

Contents

Executive Summary

Good oral health contributes to appearance, comfort, well-being, self-esteem, self confidence and social acceptability as well as to good general health. Evidence confirms that people with learning disabilities have a lower uptake of screening services (Howells, 1986, Whitfield et al., 1996, Band, 1998) and poorer oral health when compared to the general population.

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 approach which is focused on integrated care. They target a wide audience and should be made available to all those individuals and groups concerned with the health and welfare of people with learning disabilities.

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 check (assessment) will help to identify any changes in the mouth and can aid appropriate diagnosis and treatment if reported to the dentist at an early stage.

These 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 originally gathered from consultation groups of people with a mild to moderate learning disability and from postal questionnaires. These Guidelines have been reviewed and updated in line with current evidence-based practice. The full guidelines are accessible 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**).

Whilst the guidelines explore the barriers to good oral health for people with a learning disability, their main emphasis is on the prevention of oral diseases and the maintenance of good oral health. The guidance and recommendations made for all age groups are based on:

- Dietary recommendations that are in line with healthy eating policies (see Section 3)

- Good oral hygiene regimens with the use of fluoride toothpaste and regular visits to the dentist as key messages for both health care professionals and carers for people with learning disabilities (see Section 3)

- Practical information on the provision of oral health care, aimed directly at the service user, parent and carer (see Section 4)

- Gold standard guidance on appropriate commissioning of oral health care services for people with a learning disability, with the emphasis on the prevention of oral and dental diseases (see Section 5)

- Training needs in the provision of oral health care for people with a learning disability aimed at health care professionals (at both undergraduate and postgraduate levels) and to carers for people with learning disabilities (see Section 6)

- The current UK legislation related to capacity, consent (see Section 7), and Clinical Holding

- Understanding the role of voluntary organisations concerned with the welfare of people with a learning disability, and how to work together with these organisations (see Section 8)

Suggestions for areas of Further Research can be found in Section 9.

A list of Useful Resources in Section 10 signposts the reader to further information available from organisations that have developed material aimed at people with a learning disability that you may wish to refer to, adopt or adapt. Finally, the Glossary in Section 11 explains terms used, with which you may not be familiar.

These Guidelines now link closely to other recently circulated Guidelines. For example: the Department of Health documents '*Valuing People's Oral Health*' and '*Delivering Better Oral Health*'; and many of the guidelines produced by the British Society for Disability and Oral Health (BSDH) such as guidelines on '*The Provision of Oral Care under General Anaesthesia in Special Care Dentistry*' and '*The Delivery of a Domiciliary Oral Healthcare Service*' and '*Principles on Intervention for People unable to comply with routine dental care*'.

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

The next step is to develop robust quality outcome indicators underpinned by clinical care pathways, algorithms and clinical protocols.

The next full review of this document will be in five year's time and is scheduled for 2017.

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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. When our daughter, Anne, was born 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 advised us not to worry, "She is just slow!" However we insisted things were not right and when Anne was eleven months old, she saw a paediatrician who diagnosed that 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 and your partner are told and supported by the professional people involved, the nature of the disability and your ability to rationalise the situation.

Once the initial shock subsides, it is not unreasonable to expect that there will be available, a high level of expertise, knowledge and services geared to helping you raise and educate your child, and that this would extend into 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 care is important for us all. We first became aware of the special importance of good oral health for someone with a learning disability when a dental hygienist addressed a local MENCAP meeting. Given this importance, it is amazing that so much is left to chance and geographical location. General training in hygiene and access to dental hygienists, nurses, dentists and anaesthetic teams, who have the specialist knowledge, skills and experience is variable. Some primary care and hospital trust executives and managers fail to understand and cater for the special needs of people with a learning disability, and their families. The care that parents provide in the early stages is crucial and determines good oral health in later years, but they need support and guidance from the specialist dental team.

Anne is now an adult and in full time residential care. She is profoundly disabled 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 available at an early stage, almost certainly she would have suffered early loss of teeth through tooth decay and/or 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 well-being of people with a learning disability on this important subject.

Ron Franklin

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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 together with 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 were originally 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 of these Guidelines is to improve the oral health of people with learning disabilities by increasing the knowledge and skills of all those involved in the provision of their care.

The members of the Development Group for Community Dental Practice were dentists from the Community Dental Service who were 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 brings 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.

The key people involved in the original bid for the funding were as follows:

Past Chairman, The Development Group, Faculty of Dental Surgery, The Royal College of Surgeons of England: Marcus Woof

Past President, British Society for Disability and Oral Health: Sue Greening

Past Dean, Faculty of Dental Surgery, Royal College of Surgeons of England: David Barnard CBE

Iona Loh was the Project leader for the original Guidelines and Coralie Francis was the project researcher and administrator.

The list of the original Expert panel and all the Reviewers involved in reviewing and updating the Guidelines can be found at the back of the document.

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Original Research Methodology used for the Development of these Guidelines

1. This was based on a systematic review of the literature using several data bases.

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 was achieved by setting up Focus groups in Scotland, England, Wales and Northern Ireland. These groups included people with learning disabilities, parents, professional carers, Residential Home Managers, and members of the dental profession, who were consulted on their views relating to oral health and dental services within their specific geographical area.

4. A Questionnaire was designed and sent out to people with learning disabilities via MENCAP, ENABLE and the Down 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.

These Guidelines have recently been updated with a review of contemporaneous evidence and Guidelines of relevance.

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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 multidisciplinary care for people with learning disabilities.

The guidelines are therefore **aimed at everyone** involved in the care of people with learning disabilities - including service users, their parents and families, carers and advocates, health and social service commissioners and providers, dental and health professionals, education and training establishments, private and voluntary sector organisations, and planners and politicians.

The aim is that all the subjects and material will be of interest to you, and will be read accordingly. However, due to the comprehensive and diverse nature of the guidelines, you may find that some sections are of more relevance to you in your daily work, whereas others are more useful as a resource that you can refer to, as and when required.

To help you find which sections are of most interest and/or use to you:

Please refer to the contents page, which will give details of the sections.

Recommendations will be found at the end of most sections. The recommendations are graded for level of evidence. Details of the method of grading are given on the inside of the front cover of these guidelines.

1

Introduction

People with a learning disability have a right to equal standards of health and care as the general population. However, there is evidence that they experience poorer general and oral health, have unmet health needs and have a lower uptake of screening services (Howells, 1986, Whitfield et al., 1996, Band, 1998). The impact of oral conditions on an individual's quality of life can be profound (Locker, 1992). Poor oral health may add an additional burden whereas good oral health has holistic benefits in that it can improve general health, dignity, self-esteem, social integration and quality of life (Fiske et al., 2000a). Furthermore, those people with oral and facial developmental abnormalities may have additional needs requiring special care (Griffiths, 2000, Nunn, 2006). These inequalities in access to health care for people with a learning disability were highlighted in the MENCAP report 'The NHS – Health for all?' (Band, 1998) and continue to be reported (2007, Mencap, 2004, Michael, 2008).

Special Care Dentistry is concerned with the improvement of oral health of individuals and groups in society who have a physical, sensory, intellectual, mental, medical, emotional or social impairment or disability or, more often, a combination of a number of these factors (JACSCD, 2002). There is no doubt that a large segment of the population with a learning disability will meet the criteria for Special Care Dentistry. The establishment of a Specialty in Special Care Dentistry in 2008 has now provided the foundation for professional and service development to address inequities in provision of oral care.

Data available on oral health status for children and adults with a learning disability relates mainly to specific groups. However, the overall picture is one of poor periodontal health and a greater than normal unmet need of treatment for children and adults (Shaw et al., 1986,

Nunn and Murray, 1987, Hinchliffe et al., 1988, Thornton et al., 1989, Shaw et al., 1990, Francis et al., 1991, Kendall, 1991, Shapira et al., 1998, Nunn et al., 1993, Gizani et al., 1997, Cumella et al., 2000, Gunn et al., 2003, Al-Mutawa et al., 2003, Kavvadia and Lagouvardos, 2008); see also references from Section 3. Oral health may be further complicated by medical or behavioural factors and their treatment (Department of Health, 2007, Griffiths and Boyle, 2005).

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 the standard of their non-disabled cohorts and address 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 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" (Lindsey, 1998). Learning Disability includes presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood with a lasting effect on development (Valuing people 2001).

People with a learning disability is the term that will be used throughout this document.

Health "A state of complete physical, mental, and social well-being, rather than

solely an absence of disease" (World Health Organisation, 2000).

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" (Oral Health Strategy Group, 1994). The term 'oral health' includes dental health and will be used throughout this document.

Prevalence of Learning Disability

It is estimated that there are 1.2 million people with a mild to moderate learning disability living in the UK and approximately 210,000 with a severe or profound disability (Valuing people 2001). More males than females are affected, with about one quarter being children aged under 16. Approximately a quarter of the total population with a learning disability are profoundly impaired with additional disabilities. There has been little change in the number of people known to have a learning disability aged over 20 years and a small increase in the number living at home, with a migration from hospital to community accommodation.

The Foundation for People with Learning Disabilities provides relevant statistics on the current situation in England (**www.learningdisabilities.org.uk**):

• There are 55,000 – 75,000 children with moderate or severe learning disability

• There are an estimated 210,000 people with severe and profound learning disabilities: around 65,000 children and young people, 120,000 adults of working age and 25,000 older people

• Sadly, only 20% of adults with a learning disability are known to learning disability services

• The number of adults (aged over 20) with a learning disability is predicted to increase by 8% in 2011 and by 14% in 2021 (Emerson and Hatton)

• The number of adults with a learning disability over 60 is predicted to increase by 36% between 2001 and 2021

The increase can be explained by increased life expectancy, especially among young people with Down syndrome, growing numbers of children and young people with multiple disabilities who have survived into adult life, a sharp rise in the numbers of school age children with autistic spectrum disorders, some of whom will also have a learning disability, and a greater prevalence among some minority ethnic populations of South Asian origin.

Medical Problems

People with a learning disability have an increased prevalence of physical and sensory impairments, behavioural problems and epilepsy, which increase their health needs (Kerr et al., 1996). 40% of people with Down Syndrome suffer from congenital heart defects and immunosuppression. Schizophrenia, delusional disorders, autism and behavioural disorders are similarly reported to have an impact on their oral health and dental management. (Cooper, 1997a). There is a higher rate of dementia among older people with a learning disability than the general population (Cooper, 1997b) and this rate will increase with the predicted 36% increase in the learning disabled population reaching 60 years of age. These factors have an impact on oral health, on the individual's ability to co-operate for the maintenance of oral hygiene and dental management. Inability to co-operate for dental treatment can lead to a significant need for treatment under sedation or general anesthesia and to alternative techniques for behaviour and anxiety management (Griffiths, 2000, Manley et al., 2000)

Patterns of Care and Support

Patterns of care and support for people with a learning disability underwent major changes in the twentieth century. The concept of normalisation, reinforced by legislation (Department of Health, 1990), led to closures of long-stay institutions and the 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. 60% of adults with a learning disability now live with their families.

Many of those who live in supported accommodation, are situated away from their home area, which inevitably leads to restricted family contact.

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 (Band, 1998). Adherence to a social model needs to include appropriate attention to health, both in terms of life-style and access to health services (Forshaw, 1996). While the primary need of adults with a learning disability is for social care, they often also require support from health professionals (Social Services Inspectorate, 1998). Without the encouragement and active intervention of caregivers, many would not gain access to basic health services (Fiske et al., 2000a).

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 (Greening, 1999). 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 a learning disability live in their own homes, a networking approach between health, statutory and voluntary agencies providing care and support, is a primary requirement.

Philosophies of socially valued roles and social integration (Wolfensberger, 1980) have led to encouraging changes to support people with a learning disability and help them to achieve their full potential in society (Sperlinger, 1997). Joint Care Planning Teams have been developed to facilitate inter-agency working and overcome barriers. They work together with people who have learning disabilities (Rose, 1995). 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 (Social Services Inspectorate, 1998).

Person Centred Planning ensures that the person is at the centre of planning their own life. It is a process of continual listening and learning, focused on what is important to someone now, and for the future, and acting upon this with their family and friends. (Families Leading Planning)

This document aims to support and facilitate inter-agency collaboration by addressing the oral health needs and demands of people with a learning disability.

The European Convention on Human Rights, *the Human Rights Act* (1998), the *Disability Discrimination Act* (1995) and the *Equality Act* (2010), have led to changes in attitudes and policy and to the assertion that people with a learning disability 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 (Mental Health Foundation, 1996)

The development of community care has created issues of choice and quality of life, which are central to addressing improvements in oral health care (Haavio, 1995). 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. Ninety per cent of children and sixty per cent of adults living at home rely on family members or care-givers to access basic health services (Mencap Information Services, 2000). 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 (Schalock, 1996). 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 (Schalock, 1996, Campo et al., 1996).

Quality of life issues are increasingly important in the debate about the aims and effectiveness of services for people with a learning disability (Hatton, 1998). Emphasis has also been placed on the importance of subjective indices (Schalock, 1996) since such assessments are regarded as being central to an authentic model that respects the aspiration of the individual (Hatton, 1998).

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 (Chen and Hunter, 1996). Models for assessing quality of life need to bring together the medical and socio-environmental approach, which combines effect of disease and nonmedical factors (Locker, 1996). 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 impairment; people with a learning disability have the same rights as all other members of society.

Dental services should be provided in a way that:

- Recognises everyone as an individual
- Recognises that everyone has a right to participate in decisions that affect their lives
- Provides the amount of support necessary to enable everyday living, including adequate health care (Clark and Vanek, 1984)

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

(Clark and Vanek, 1984)

2

Barriers to Oral Health

The barriers to oral health that people with a learning disability 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, impairment, disability, socio-economic status and the stresses imposed upon daily living for the individual, family and carers (Griffiths, 2000). Oral health may have a low priority in the context of these pressures and other medical complications and disabilities, which may be more life threatening (Ohmori et al., 1981). Hence it may require a change in attitude and practice for parents/carers to include oral health as part of routine care (Kenny, 1999). Routine oral health care and regular maintenance improves comfort, function and self esteem and is likely to reduce the need for extractions rather than fillings. It also avoids a crisis management approach for pain relief, sometimes requiring the person to undergo a general anaesthetic to enable the treatment to be successfully completed.

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. A lack of perceived need, inability to express need, and lack of ability for self-care, are also user barriers to accessing and utilizing dental services. (Kendall, 1992).

Parents/carers face challenges in providing a recommended healthy and nutritional diet for an individual with eating or drinking difficulties. In addition, a necessity for high calorie food supplements, sugar based liquid medication and laxatives may increase the risk of dental caries. These problems can be countered by enlisting the help of parents, carers and the dental team to instigate programmes to prevent oral diseases as part of the individual's daily routine. Since poor standards of oral hygiene exist in all age groups (Francis et al., 1991, Gizani et al., 1997, Hinchliffe et al., 1988, Kendall, 1991, Nunn et al., 1993, Nunn et al., 1995, Nunn and Murray, 1987, Shaw et al., 1990, Shapira et al., 1998, Shaw et al., 1986, Thornton et al., 1989), parents and carers are likely to need training in order to carry out these programmes effectively whatever the age of the child or adult under their care.

The majority of people with a learning disability have poor verbal skills and are restricted in their ability to communicate their needs (Howells, 1986), 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 (Low et al., 1999).

Young adults with learning disability believe oral health, freedom from pain and good appearance are important (Doshi et al., 2009).

Fear and anxiety are the most common barriers to dental care (Finch et al., 1988) and people with learning disabilities are no different from the wider population in this respect (Band, 1998, Gordon et al., 1998, Russell and Kinirons, 1993). However, it may be harder to discuss and resolve those fears. Dislike of dental treatment is significantly related to irregular dental attendance (Russell and Kinirons, 1993). Inability to cooperate with treatment leads to

a greater need for behaviour management techniques, conscious sedation and general anaesthesia than for the general population (Forsberg et al., 1985, Kendall, 1991, Nunn et al., 1993, Gordon et al., 1998, Connick and Barsley, 1999, Davies et al., 1988).

Policies for self-empowerment, freedom of choice and Clinical Holding, may create problems with dental attendance (Shaw et al., 1990, O'Donnell, 1985), with many service users unable to seek care without support (Mann et al., 1986a).

Lack of parental awareness is a major contributory factor for low dental attendance in children who have a learning disability, (Lo et al., 1991) being less likely than their contemporaries to have had a dental check-up in the previous year (Office for National Statistics, 1999). Greater travelling distance, because the disabled child requires specialist care and appropriate services that are not available locally, may also contribute to less frequent attendance (Nunn and Murray, 1990).

Community home managers often identify residents' reluctance to accept care as being a barrier to dental attendance (Pratelli and Gelbier, 1998). Poor uptake of dental services is reported when the responsibility for accessing care is transferred to adults with a learning disability and their support workers, even when there is a high level of support from the dental team (Wales, 1996).

The knowledge and skills of carers, whether family or professional, have an impact on the oral health and their perception of need may influence the frequency of contact with dental services for people with a learning disability. Their knowledge and practice of oral health care has generally been demonstrated to be inadequate (Bowsher et al., 1999, Hunter et al., 1996, Longhurst, 1998, Rak and Warren, 1990).

A lack of relevant vocational qualifications and high staff turnover in supported accommodation provided by voluntary and private organisations has implications for staff training (Felce et al., 1993). These training needs are addressed in guidelines developed by the British Society for Disability and Oral Health (Fiske et al., 2000a). Training programmes should stress that poor standards of oral hygiene can be a serious health threat (Eadie and Schou, 1992, Lewis, 1984, Trenter and Creason, 1986) and should address the needs of all grades of staff and shift patterns (Boyle, 1992, Nelson, 1988). Providing training alone is not sufficient to promote behaviour change and the attitudes and values of carers also need to be addressed (Frenkel, 1999).

The use of focus groups including parents of children with a learning disability, can provide valuable insights into parent issues and perceptions (Slack-Smith et al, 2010). Focus groups give participants the opportunity to share their experiences, which can be helpful in service planning and training.

Qualitative research was used to explore the subjective experiences of people with learning disabilities, and their carers in relation to access to dental services (Owens et al, 2011). It concluded that although policy and guidance is available and prescriptive, it has so far been ineffective in improving access and consequently, the quality of oral health care for people with learning disabilities. A modified model of access is suggested linked to guidance by the British Society of Disability and Oral Health, to inform the commissioning of services that enable optimum access to quality care.

2.2 Professional Service Providers (Barriers)

Dentists within the Salaried Dental Services treat and care for different populations of patients with special needs and a continuum of service provision potentially exists (Freeman et al., 1997). However, previous surveys of new dental graduates have demonstrated low confidence scores in the management of such patients (Matthews et al., 1993) and inadequacies in professional training for dentists and hygienists have been reported (Bickley, 1990, Erridge, 1986). Dentists' lack of experience of learning disabilities and the financial constraints of the system of remuneration in the NHS may be contributory factors, creating further barriers to accessing dental care (Connick and Barsley, 1999). Carers believe that, on the whole, dentists prefer not to see patients who may present a problem to them (Band, 1998).

However, The *Disability Discrimination Act*, (1995) 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 (Gooding, 1995). 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 (Freeman et al., 1997) suggestions have been made to improve the situation (Nunn and Murray, 1988). These include improved quality of undergraduate and postgraduate dental training, plus increased access to this 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 (Pratelli and Gelbier, 1998). Training in the care of people with disabilities should be available for all members of the dental team (Oliver and Nunn, 1996), although it has a low priority in many dental schools (Wilson, 1992).

These issues are being addressed by the Teachers Group of the British Society for Disability and Oral Health (Nunn et al., 1995), resulting in new clinical teaching programmes and outreach training for dental undergraduates. A certified course for dental nurses in special care has been introduced by the National Examining Board for Dental Nurses (www.nebdn.org). In 2009, Cardiff University Dental and Medical Postgraduate Section established a postgraduate diploma for dental health professionals; which includes two distance learning modules on Special Care Dentistry and is aimed primarily at dental hygienists and therapists; details of this initiative are on the postgraduate website (www. dentpostgradwales.ac.uk/dcp/nurses.htm).

The first postgraduate training programme and training posts in Special Care Dentistry were established in 2009, with dentists due to complete their 3 year training programme in 2012.

The development of a Tricollegiate examination in Special Care Dentistry has been ongoing, with the first diet of the examination due to take place in June 2012.

A study exploring the attitudes of Community Dental staff towards disability, disabled people and the provision of dental care for disabled people, revealed evidence demonstrating that these staff held attitudes in support of the social model of disability (Scambler, 2011).

Patient centred care, adapted to ensure that the needs of all patients could be adequately met, was at the heart of the model. Communication was key, plus adequate time, trust, specialist training, and the fact that skills were honed over time.

2.3 Physical 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 (O'Donnell, 1985, Beardshaw, 1988, Finger and Jedrychowski, 1989). There may be significant costs in terms of physical effort; emotional effort and financial outlay to gain access to oral care (Griffiths, 2000).

Difficulties may arise from e.g. ambulance transfer, availability of taxis with wheelchair access.

Data gathered from the consultation groups during the preparation of the first edition of these guidelines confirmed that participants knew the importance of oral health, oral hygiene and diet. Either the parent, carer or the dentist (via a reminder letter) arranged attendance for oral care. Despite the perception of their oral health being "quite good" all 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 Cultural 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 (NHS SSI Executive, 1999), including language. There are different customs and practices between cultures and it is important to be aware of them and how they may impact on the use of dental services.

People from ethnic minority groups may have different attitudes and beliefs about oral matters. Females may prefer to be seen by a female dentist (Williams et al., 1991, Doshi et al., 2009). 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 (NHS SSI Executive, 1999). Oral health promotion and acclimatisation to the dental environment are, therefore, very important for this group. Cultural variation in ethnic minority groups may have difficulty in communicating their needs. This can act as a barrier, resulting in dental needs not matching attendance at the dentist. There is an expectation that the number of people with a learning disability from ethnic minority groups will increase (Williams et al., 1991). 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 oral health messages have been delivered. There are some packages available including the Homefirst manual and Oral Health Leaflets published by Mencap, the Hospital Communication Book – see Section 10 Resources. Use of photographic material and the three face 'Smiley Face Scale' can help adults from ethnic minority groups with learning disability to express their needs, wishes and views (Doshi et al., 2010).

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, socioeconomic status, 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 (Gizani et al., 1997, Nunn and Murray, 1987, Shaw et al., 1986, Nunn, 1987, Pope and Curzon, 1991, Palin et al., 1982).

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 Salaried Dental Services (Evans et al., 1991). In institutions, lower dental caries prevalence may be related to restricted access to a cariogenic (high sugar) diet (Forsberg et al., 1985). Children with Down Syndrome have a lower prevalence of dental

caries due to later tooth eruption and abnormal tooth morphology (Chan, 1994, Russell and Kjaer, 1995, Stabholz et al., 1991). In children with mild learning disabilities and children who are partly independent, dental caries prevalence is higher (Palin et al., 1982, Storhaug and Holst, 1987). It would appear that these children may have fewer dietary restrictions and are therefore at greater risk of developing dental caries.

All studies report uniformly poor standards of oral hygiene and plaque control, and poorer periodontal health in children with learning disabilities (Forsberg et al., 1985, Gizani et al., 1997, Nunn and Murray, 1987, Shaw et al., 1986, Palin et al., 1982, Pope and Curzon, 1991, Evans et al., 1991, Storhaug and Holst, 1987). A high proportion of children in special schools have periodontal disease (Nunn et al., 1993, Evans et al., 1991). Gingival enlargement/overgrowth affected 20% of children with a severe or profound learning disability (Forsberg et al., 1985). Children with milder learning disabilities not receiving treatment, have the poorest gingival health (Palin et al., 1982). Gingivitis (inflammation of the gums) and periodontal disease is more severe in children with Down Syndrome even when a good standard of oral hygiene is maintained. This is thought to be linked to the compromised immune system.

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 (Royal College of Surgeons, 1999) with appropriate information on caries/periodontal health.

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 (Nunn and Murray, 1987)(*Figures 1 and 2*). Education coupled with close collaboration with specialist services (Elksnin, 1997) facilitates the early identification of children who may be at risk. Ideally, a dentist should be included in the inter-disciplinary team (Griffiths, 2000), ultimately resulting in more comprehensive and cohesive care. However, the changing role of special schools and integration into mainstream education create challenges for identifying the children at risk of developing gum disease and caries. (Greening, 1999).

Multidisciplinary working within oral health care centres for children and adults with Down Syndrome, is vital to encouraging parents, primary care workers and oral care professionals to work co-operatively to maintain oral health (Bouvy-Berends et al, 2010), Client-centred care is mandatory for optimal oral health in this vulnerable group.

Diet

Sugars are not only detrimental to oral health, but can also have a negative impact on general health (C.O.M.A., 1989). 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 (Nutritional Task Force, 1994).

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 (C.O.M.A., 1989) and where possible prescribe sugar free alternatives. (The National Pharmacy Association have produced a leaflet on "Sugar free Medicines" which lists the sugar content of branded oral liquid medicines). Most

medicines are now available in a sugar free alternative (Department of Health, 2009a).

In pre-school children, the consumption of sugars is double the recommended maximum (Moynihan, 2000). 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 (Nunn and Murray, 1987).

It is recommended that there is a reduction in both the frequency and amount of added sugars consumed.

It is important that parents and carers are aware that honey, fresh fruit juice and dried fruit all contain cariogenic (decay producing) sugars.

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 (Royal College of Surgeons, 1999).

A diet diary should establish the following information:

- Number of food/drink intakes per day
- Number of sugar containing intakes (excluding those found in whole fruit)
- How many consumed between meals
- How many within one hour of bedtime

Dietary supplements should be given at meal times, whenever possible. Provision of supplements to alleviate the symptoms of dry mouth should also be considered when appropriate. See Resources: **www.patient. co.uk/healthdry-mouth.htm**

Recommended breastfeeding and weaning practices should also be promoted. (**www. breastfeeding.nhs.uk**) (Department of Health, 2008d).

Discontinuation of night time bottles by 12 months should also be encouraged with introduction to drinking from a cup from as early

an age as possible, depending on the disability/impairment. Encourage water as a substitute for milk at night.

Oral Health Education

Poor standards of oral hygiene and plaque control, together with poor standards of oral health are reported in disabled children (Nunn, 1987).

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. It is advised that gentle brushing can be initiated from birth (without toothpaste), prior to any teeth erupting. This allows children to get into the habit of allowing their parents to access their mouths as early as possible before teething creates potential discomfort.

The technique itself, 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 dexterity and 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.

Use of Fluoride

Children with learning disabilities are in a high-risk category of developing dental caries, and the principles that apply to pre-school children, apply equally to older children and adolescents (Royal College of Surgeons, 1999). Recommended doses of additional fluoride will depend upon the levels of fluoride in local drinking water.

Fluoridated Toothpaste

It is recommended that brushing with a family fluoride toothpaste is initiated as soon as the first tooth erupts. Children under the age of 3 years should only use a smear of toothpaste 1000ppm and those aged 3 -6 years should only use a pea-sized amount of 1000ppm. Children who are 7+ should be using 1350-1500ppm. (Towards Better Oral Health NHS England 2009 and Prevention and Management of Dental Caries in Children 2010.)

Brushing should be at least twice daily.

Children who have an increased caries risk and those with an impairment or disability, should use toothpaste containing 1350 – 1500 ppm fluoride from 3 years of age.

2800ppm should be considered for children over 10 years of age, who have a higher risk.

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. Some children may be at greater risk of ingesting toothpaste; therefore adult supervision is essential to monitor the quantity of toothpaste used (Chan and O'Donnell, 1996). 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, depending on the levels of dexterity and independence. Every step should be taken to ensure optimal oral hygiene for the child.

N.B. Mouthrinses are **not** recommended for people who have swallowing difficulties.

Children may also benefit from the application of professionally applied fluoride varnishes.

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 any smooth surface lesions in primary teeth or roots of permanent teeth. The application of fluoride varnish in simple and systematic reviews has demonstrated that twice-yearly applications

produce a mean caries incremental reduction of 33% in the primary and 46% in the permanent dentition. The patient should be advised to avoid eating, drinking or toothbrushing for 30 minutes after application.

Early Periodontal Problems

A number of studies (Nunn, 1987, Vigild, 1985) have indicated that children with learning disabilities have more plaque on their teeth and increased levels of 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 (Vigild, 1985).

Children with Down Syndrome are susceptible to a more generalised aggressive form of periodontitis due to immunodeficiency. This can result in bone loss and deep gingival 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.

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 (Collacott, 1996). 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 (Jackson, 1979). However, such advice may be missed if parents are perceived to be unreceptive (Quinn, 1991). (Investment in more health visitors under government programmes is a positive measure).

Identification of oral health needs as part of general healthcare needs assessments, facilitates early contact with dental personnel. Health Boards, PCT's and Strategic Health Authorities have a responsibility to disseminate information and facilitate these processes through the resources of the Salaried Dental Service (SDS) and Hospital Dental Service (HDS). Overall, a patient-centered approach is required, as detailed in 'Our Health, Our Care, Our Say'.

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 (Fraser et al., 1998).

Working positively with the health visitors increases registration of pre-school children attending the CDS (Bentley and Holloway, 1993).

- Dental Care Exemplar developed for a child diagnosed with impairment and disability

- The Exemplar takes you through the patient's journey, including prevention and treatment, with recommendations and an evidence base. (Valuing People's Oral Health 2008)

- A VDP Project carried out in Bracknell Forest PCT Community Dental Service in 2006 involved paediatricians and dieticians, who encouraged consistent dental health education advice for children with chronic illnesses or on high sugar/calorie diets (Department of Health, 2007). (Valuing People's Oral Health 2008)
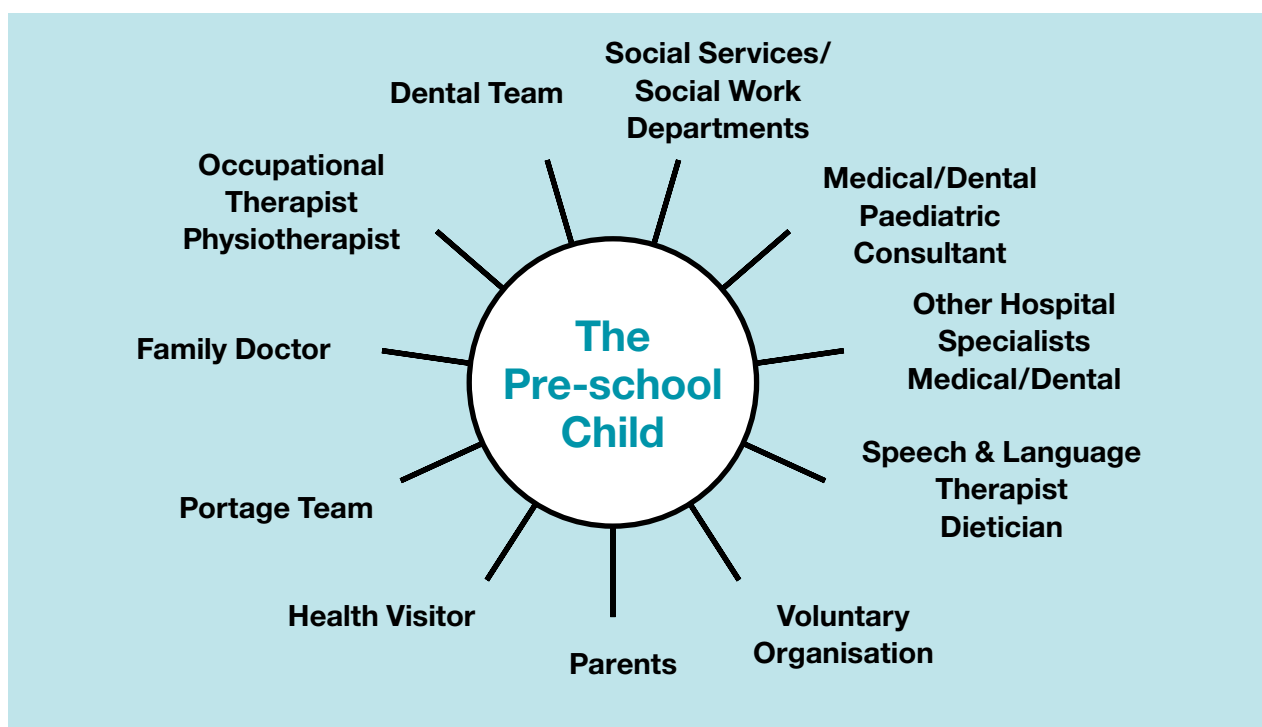
Figure 1: Integrated Care for the Pre-school Child

- Introduction of a Special Smiles Project in Surrey which encouraged early dental referral of children with complex medical problems and learning disabilities by Paediatricians and Health Visitors, resulted in instigation of robust preventive programmes, together with acclimatisation to dental visits, from 6 months of age.

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.

Examples of Good Practice

The establishment of a mobile dental service for children requiring special care and the development of training programmes for carers and the dental team within inner city London (Lisowska, 2000).

By preparing and including a consent form in advance for dental care, and by placing it within the child's health record, it encouraged health visitors to gain consent for advice and referral (Harker, 1991) for oral care.

Regular Attendance

The majority of children with disabilities use the Salaried Dental Services, but less than half attend regularly (Nunn and Murray, 1990). Children who only attend when in pain have been found to have more decayed and missing teeth and fewer fillings than regular attenders (Nunn and Murray, 1990). The evidence points to the need to carry out a risk assessment with regards to oral health and, if appropriate, 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.
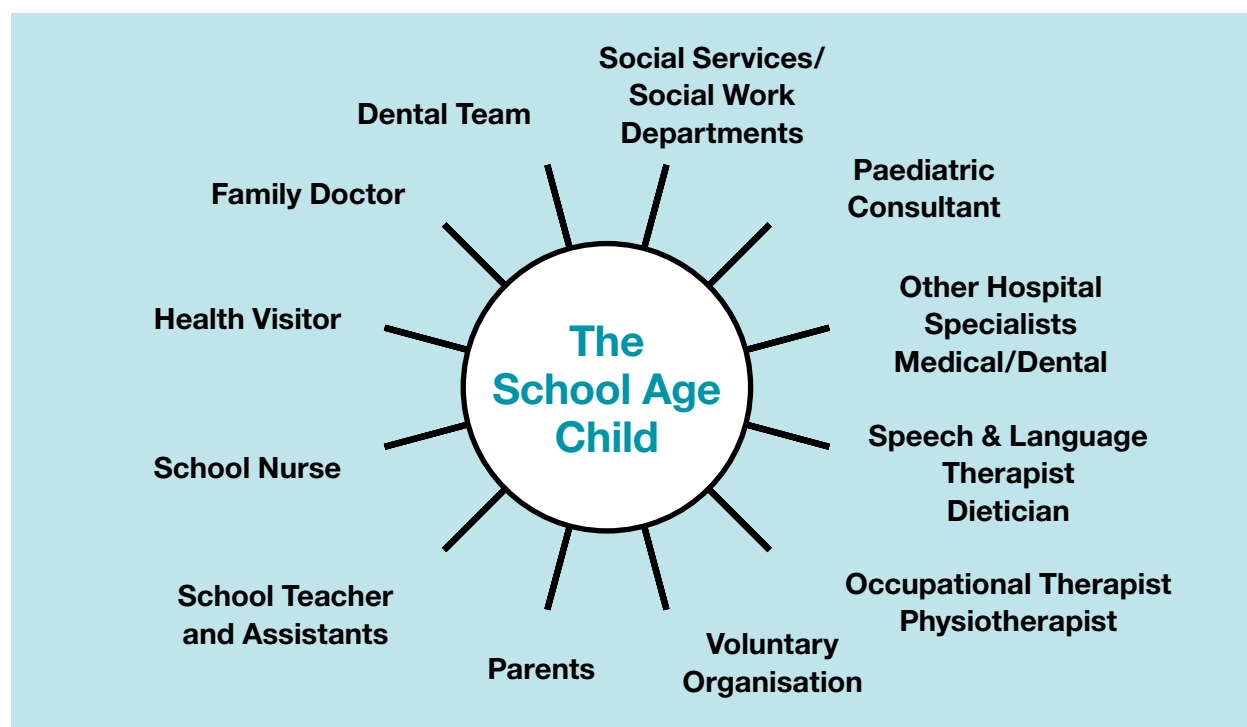
Figure 2: Integrated Care for the School Age Child

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 SDS in compliance with health directives (Department of Health, Gateway Reference 7698. 2007).

Screening used to be carried out on at least three occasions during a child's school life. In special schools, this process may be more frequent. The National Screening Committee found screening 6-9 years old, to be of no value at all.

Decisions regarding whether or not to continue with screening are a matter for each individual commissioning boards and PCT's. In areas of the country where oral health is poor and screening can be shown to be effective in reducing levels of untreated dental disease, there may be a case for continuing to commission a screening programme but this would now be subject to obtaining positive consent from parents/carers. If screening is discontinued, any resources freed up should be used in other ways for reducing oral health inequalities.

Example of Good Preventive Practice Case Study

An epidemiological survey revealed that 5 years olds attending Special Needs schools had far higher levels of dental decay, and tooth extractions due to the disease, than children attending local mainstream schools (Department of Health, 2007).

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, only for special needs schools, may no longer be acceptable in this context. However, mobile dental services where available, can help parents who have difficulty 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 (Department of Health, 1991).

A number of epidemiological studies show that soft drinks are associated with erosion and the World Health Organisation recommends that the amount and frequency of intake of soft drinks and juices should be limited. If the child is also suffering from gastric reflux or vomiting, tailored and specific advice will be required coupled with close liaison with the child's GP and Paediatrician.

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 and/or behaviour management techniques. 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 in an appropriate manner (e.g. Makaton or visual pictures) 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.

Time, patience and an experienced dental team are required to enable most children with learning disabilities to 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 (Department of Health, 2000a).

Fissure Sealing

Children requiring special care dentistry are a priority group for the use of fissure sealants (Royal College of Surgeons, 1999). However, the success of this treatment depends on patient compliance.

Example of Good Practice

A Protocol for Dental Needs Assessment of Special Needs Children to assess co-operation and to determine patient management, was 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 (Lunn and Williams, 1990).

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 (Huston et al., 1992). 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

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 surgical and/or repeated restorative treatment.

Regular Dental Visits

These need to be encouraged at every opportunity, with recall intervals in line with NICE recommendations, taking into account individual oral risk factors. Establishment of appropriate links and liaison will promote continuity of care. Parents/carers should be made aware of the role of the Salaried Dental Service (SDS) as a primary dental care service with the necessary expertise. The decision on whether to choose the General Dental Service (GDS) or Salaried Dental Services, should be discussed with parents or carers. It is expected that the GDS would refer patients when necessary to the SDS when Specialist expertise is required or when physical access problems exist.

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
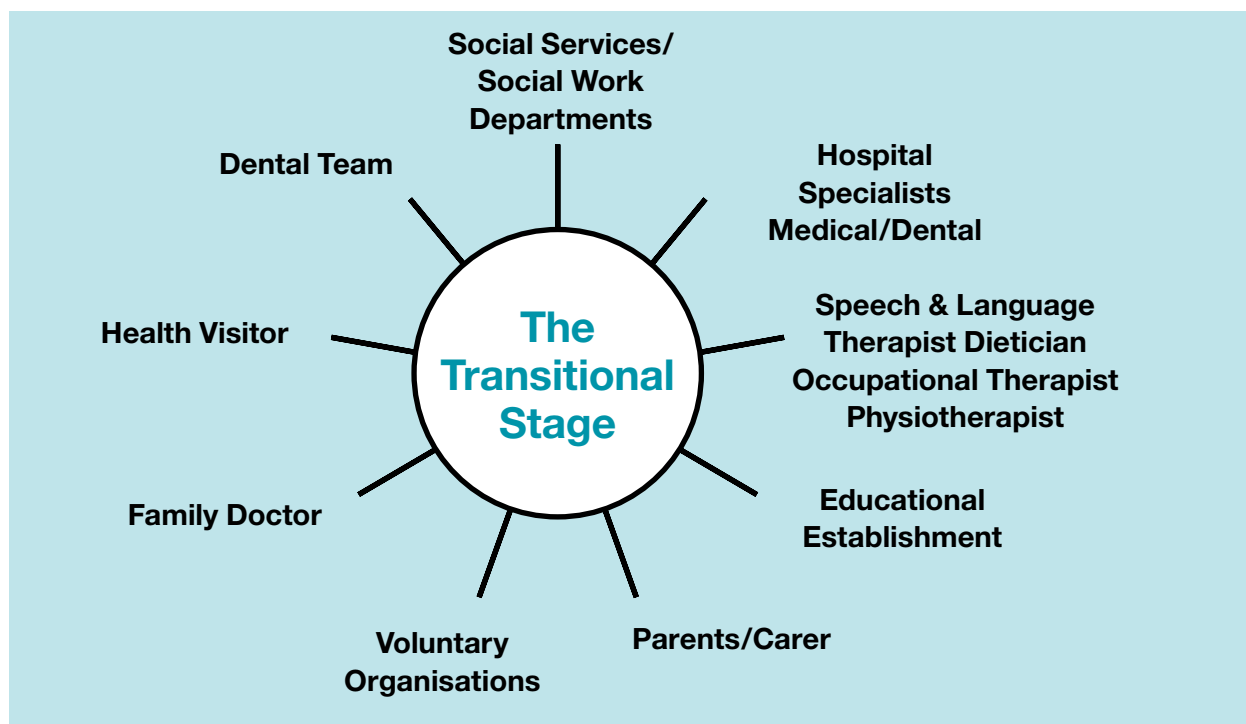

Figure 3: Integrated Care for the Transition Stage

aware of the likely exposure of their children to addictive substances such as tobacco.

3.3 Young Adults through to Older People

Introduction

Dental disease patterns and oral status of adults in the UK are changing (Office for National Statistics, 1999). The general trend is an increase in the retention of natural teeth until later in life (Office for National Statistics, 1999 and Adult Oral Health Surveys). 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 (Locker, 1992, McGrath and Bedi, 1998).

People with learning disabilities generally experience the same oral problems as the general population. However, poor oral health is an additional problem to deal with, whereas 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 (Francis et al., 1991, Hinchliffe et al., 1988, Shaw et al.,

1990, Nunn, 1987, Pieper et al., 1986).

A more recent study of adults who were not in contact with the Salaried Dental Service, showed higher levels of untreated dental caries and periodontal problems than the general population. They also demonstrated increased levels of untreated caries and periodontal disease than in the previous studies where the SDS provided care (Whyman et al., 1995). High levels of periodontal disease are consistently associated with poor standards of oral hygiene which highlights again the importance of training, support and regular care.

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 profound disabilities (Kendall, 1992, Hinchliffe et al., 1988). Oral hygiene has been found to be better in those with mild learning disabilities (Kendall, 1992) and the poorest oral hygiene has been reported in those with additional disabilities (Shapira et al., 1998, Shaw et al., 1990).

The dental care received appears to be related to the individual's ability to comprehend or co-operate with treatment (Francis et al., 1991) resulting in a significant number of adults require treatment under general anaesthesia (Francis et al., 1991, Whyman et al., 1995).
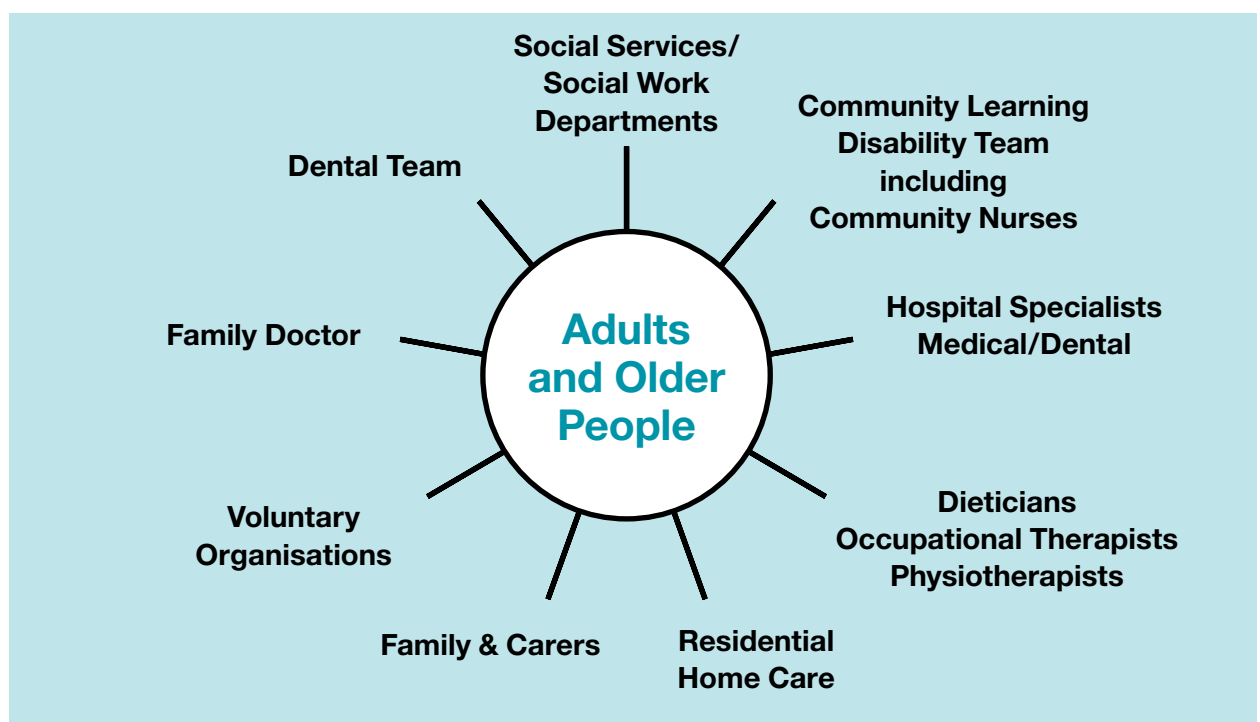
Figure 4: Integrated Care for the Adults and Older People

A study on the oral health of older people living in nursing homes, demonstrated that only a third of the physicians carried out a systematic oral examination, and the majority were in favour of being supplied with more information on oral diseases and regular dental visits (Chung, 2008). The physicians also felt that close collaboration with a dentist on oral health issues was a low priority.

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 (Hinchliffe et al., 1988).

Health and Social Care Policies

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 (Wolfensberger, 1980) and Social Role Valorisation, adopted in the last decades. Oral healthcare has not escaped these influences (Rippon, 1988). 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 (Evans et al., 1994, Great Britain, 1990).

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 (Department of Health, 2000b).

Diet and Nutrition

The influence of diet and nutrition on oral and general health is an issue, which must be addressed (Shaw et al., 1990, Steele, 1989).

Dental health is linked to good general health and happiness. There is evidence that aesthetically acceptable and functionally adequate dentitions affect self esteem, confidence and socialization (Fiske et al., 1998, Simons et al., 1999, Steele et al., 1998). 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 (C.O.M.A., 1989). 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 (C.O.M.A., 1992). The Nutrition Task Force emphasises the importance of providing simple, practical and realistic guidance for selecting a balanced diet (Nutritional Task Force, 1994). 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 (Fiske et al., 2000b).

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 (Shaw et al., 1990). In those with mild learning disabilities, this may be very appropriate and use of dental hygienists to provide successful training is well documented.

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 (Fiske et al., 2000a). 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 (Quinn, 1991), together with the lack of personal perception of oral health problems by individuals themselves (Lester et al., 1998, McEntee et al., 1985).

Currently, guidelines within community homes do not always routinely include oral care and insufficient 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 (Glassman et al., 1994, Mann et al., 1986b).

Well performed preventive programmes can prevent the progression of periodontal destruction in people with Down Syndrome (Cichon, 2011). The programmes recommended include oral hygiene instruction, individually tailored techniques, with professional cleaning, followed immediately by administration of a 0.2% Chlorhexidine spray.

Another study on a group of people with Down Syndrome, conducted over a period of 2 years, investigated the effects of different applications of chlorhexidine as a gel or varnish in different strengths (Freedman, 2011). There were few, significant differences between concentration, formulation or frequency of chlorhexidine on clinical measures of periodontal disease.

Chlorhexidine gel (1%) applied daily within the home environment, plus a 6 monthly prophylaxis, was as effective and efficient in maintaining periodontal health. Chlorhexidine varnish (40%), when applied 6 monthly can also offer benefit, but may cause some difficulties with eating.

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

Examples of Good Practice

Development and audit of quality standards established with the co-operation of the dental team and care staff in community group homes, plus the use of oral assessments. Community Dental Services. (Community Dental Services Gwent Health Care 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 (Nicolai and Tesini, 1982). Oral health input into staff induction programmes can overcome some difficulties in releasing staff for separate specific training sessions (Davies and Whittle, 1990).

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 as in Health Action Groups. Inclusion at this level should ensure translation into local strategies, encouraging a greater uptake of 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 (Greening, 1999).

Example of Good Practice

Development of Oral Care Plans in Surrey Community Health, Special Care Dental Department for all adults with learning disabilities.

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 (Royal College of Surgeons, 1999). The complexity of treatment provided may be influenced by the severity of the learning disability (Kendall, 1992, Hinchliffe et al., 1988, Shaw et al., 1990). Studies report consistently poor periodontal health associated with poor oral hygiene (Shaw et al., 1990, Hinchliffe et al., 1988, Davies and Whittle, 1990), which directly influences outcome and 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.

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 inhalation sedation, 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 indeed, the ability to wear the dentures once completed. Collaboration and communication are again crucial to the treatment planning process.

Uptake of oral care services can be increased by the use of mobile dental 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

Examination and, treatment of 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 (Pratelli and Gelbier, 1998). 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 (Lord Chancellor's Department, 1999). This will help to avoid unnecessary conflict and delay in providing appropriate dental 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 (See section 7 on consent). 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 issues.

Secondary Care Services – Hospital Care (see section 3.7)

Dental treatment for adults who require treatment under sedation is sometimes provided in hospital but can also be available in some health centres and dental practices. All day care and, where required, inpatient facilities for dental examination and treatment under general anaesthesia must be based within a hospital setting with critical care facilities on the same site (Department of Health, 2000a).

It is essential that seamless services, including specialist provision for treatment under sedation or general anaesthesia, are developed and secured 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 liaison 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 are available for residents leaving hospital, which health professionals can utilise to refer them onto the Community Dental Service.

The effectiveness and benefits of a direct onward referral system, 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 Sedation and Special Care Dentistry, Cardiff University Dental Hospital).

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 (Fiske et al., 2000a). Their rights to oral health and appropriate oral care services must not be overlooked.

Services for Adults with a Learning Disability

Adults with learning disabilities can be considered as follows:

- People with low support needs – those who are able to lead relatively independent lives and have a mild learning disability

- People with medium support needs – those who require assistance with a wide range of every day skills but are able to undertake a number of tasks for themselves independently. (Moderate to severe learning disabilities)

- People with high support needs – those who typically require 24-hour care as they are able to carry out only a few, if any activities of daily living. (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 (Kendall, 1992, Francis et al., 1991, Hinchliffe et al., 1988, Shaw et al., 1990, Holland and O'Mullane, 1986). The more able, less dependent adults were found to have more fillings, fewer extractions and better oral hygiene. They were also able to obtain care in the General Dental Service more than other attendees at the centres (Kendall, 1992). It is however also evident that this group was not gaining access to general health care services (Department of Health, 1998) and have been '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 were 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, may 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 used to live in institutional care but have now successfully moved to community based living in Group Homes with full time employed carers. (Rippon, 1988). Many adults with this degree of disability are unable to make their own decisions although most can indicate their likes and dislikes.

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 related to their ability to give informed consent.

Generally, the SDS provides the primary oral health care for this group (Department of Health, 1989), with dental 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 SDS should continue to develop and provide services for this group of people and work with carers/families to encourage dental attendance and to maintain good oral health at home.

3.4 Communicating with People with a Learning Disability

Impact of communication on health care

It is well recognised that poor communication can contribute to the significantly greater health needs of people with a learning disability and may result in those health needs not being met appropriately (Royal College of Nursing, 2007, Michael, 2008).

Mencap's report 'Death by Indifference' (Mencap, 2007) set out case studies relating to six people with a learning disability who died unnecessarily as a result of receiving worse healthcare than people without a learning disability. The Parliamentary and Health Service Ombudsman's report 'Six Lives' (Parliamentary and Health Service Ombudsman, 2009) reviews the reasons for the deaths and highlights the areas for concern which led to failure to offer good care. They are:

• Communication

• Partnership working and co-ordination

• Relationships with families and carers

• Failure to follow routine procedures

• Quality of management, and

• Advocacy

Although communication is mentioned in its own right, the common denominator causing failure in the other areas of concern is communication.

The importance of good communication with people who have a learning disability, with their family and carers, and with their health and social care teams, cannot be overemphasised.

As a result of the 'Six Lives' report, it was recommended that *all NHS and social care organisations in England* should review the effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with a learning disability in their areas. This includes the capacity and capability of the services they provide and/or commission for their local populations, to meet the additional and often

complex needs of people with a learning disability.

Subsequently, the Care Quality Commission (CQC) performance assessments (from 2009/10) (Care Quality Commission, 2010) include indicators related to learning disability and focus on achieving equality in access to healthcare through six domains which include:

- protocols that ensure pathways of care are reasonably adjusted to meet the health needs of people with learning disability

- provision of readily available and comprehensible information which is jointly designed and agreed with people who have a learning disability, their representative local bodies and/or local advocacy organisations, regarding their treatment options (including health promotion), relevant complaints and appointments procedures

Thus the CQC puts effective communication right at the centre of good care.

What is Communication?

The Government White Paper 'Valuing People' states that people with a learning disability should have: Independence, Choice, Rights and Inclusion. Effective communication is fundamental to achieving these principles.

Communication is a two way process involving the sending and receiving 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. It is important that the information being exchanged is understood by both parties as shared communication is fundamental to being included in a society.

Communication is a basic human right that allows us to make choices and develop our independence. Estimates suggest that 50% to 90% of people with a learning disability have communication difficulties (BILD).

There are many types of communication difficulties, including:

- Speech and/or language delay, disorder or impairment

- Expressive and or receptive language disorder

- Stuttering or dysfluency

- Verbal dyspraxia - which causes difficulty in making the muscle movements that are needed for speaking clearly and quickly

- Semantic/pragmatic disorder - which affects an individual's use of language for social purposes

- Central auditory processing disorder - which affects an individual's listening and understanding of language

- Dyslexia

- Hearing and/or visual impairment

- Difficulty focusing and sustaining attention

- Intellectual delay and disability - resulting in delayed development of speech and language

- Lack of experience, stimulation or opportunity to talk to other people

People with a learning disability do not have one recognised tool for communication and are often dependent on professional help to develop an individually, tailored communication plan. Considering communication in its broadest sense, it is essential to find out the ways individual people use to communicate.

About 60% of people with a learning disability overall, have some skills in symbolic communication using pictures, signs or symbols. About 20% have no verbal communication skills but do demonstrate a will to communicate, and expect a response (BILD).

Always try to use the best method for the person with whom you are communicating.

Communication methods include:

- **Gesture** – hand gestures, facial expression

- **Signing** – Makaton, Signalong, British Sign Language, individual methods such as blinking

- **Symbols** – pictures which represent words e.g. Widget Software

- **Photographs** – to depict a subject

- **Objects** – to depict a subject or action

- **Drawings** – used to illustrate what needs to be communicated

- **Writing** –used to relay information

- **Alternative and Augmentative Communication (AAC) devices** – for

example communication boards, light writers, computers or voice output devices

- **Speech** – it is essential to speak to the individual with a learning disability, (even if they have no speech) in addition to using other communication methods as appropriate

Whilst it is important to ensure that the individual is addressed and included in any communication, it is worthwhile remembering that family, carers and the members of the Community Learning Disability Team can be useful sources of information. For example, in eliciting the preferred method of communication or establishing how an individual expresses that they are in pain.

Accessible information

As communication is an exchange of information, we need to be clear how to make information accessible. Accessible information is simply information that is presented in a form and style that is easily used and understood by its intended audience. Making information accessible is not about watering down the content or creating a summary, but about taking information from a form that is not accessible to an individual and converting, translating or interpreting it into a form the individual can access. Accessible formats, often referred to as alternative formats, include documents and other items produced, for example, in Easy Read, in Braille, on audiotape, in large print size. The general principle is that whichever communication methods are being used, information should be clear and simple so that it is of use to the recipient and is effective in relaying the information.

Useful guidelines available for developing accessible information can be found at the site of the RNIB Digital accessibility Team at http://www.tiresias.org/research/guidelines/alternative_formats.htm

People with more severe and complex needs may not be able to use any of the recognised means of communicating. New approaches have been developed in recent years such as Phoebe Caldwell's learning through play (Caldwell, 1998), Individualised Sensory Environments, Intensive Interaction (Nind and Hewitt, 2006) as well as the technological development of multi-sensory rooms. These techniques are helping us to increase our knowledge and understanding of non verbal behaviour to enable us to respond to and encourage individuals with respect, at whatever stage they have reached in their communication development.

Assessing Communication

It is essential to assess an individual's level of understanding, method of communication and any issues they may have. Many people may be involved in this assessment including the individual themselves, family members, carers and other health care professionals such as the Community Learning Disability Team members. Speech and Language Therapists (SaLTs) are key professionals providing communication assessment and recommendations for intervention, and ideally, should be involved at an early stage. It is important to remember that levels of understanding may vary from day to day or setting to setting. For example, it may be easier for an individual to understand information away from an environment that makes them anxious, such as the dental surgery, and a one off home visit might be useful. Information should be provided in digestible chunks in an accessible format with some form of appropriate written/picture/symbol information provided for the individual and their family/carer to refer to later. Provision of accessible information is key to gaining informed and valid consent.

Understanding Communication Issues

Understanding communication issues can be complex. Assumptions may be made about communication based on personal experience. For example, an assumption that if someone speaks they must understand; if someone carries out an instruction, they must have understood the words; if someone doesn't respond to an instruction, they could not have understood it.

It is essential for everyone who lives, works or comes into contact with people who have learning and communication disabilities to receive training in the understanding of how communication works, what happens when it doesn't work effectively, and who to call on for additional help and support, (British Institute

for Learning Disabilities - BILD). Training and support may be provided by SaLTs as well as other experienced learning disability staff. Training may be generalised or tailored to individual situations as appropriate, and should be reviewed regularly.

Examples of Good Practice

"Going to the Dentist" – a book explaining routine experiences for children and adults with learning disabilities and/or communication problems (Makaton Vocabulary Development Project, 1999). This book provides photographs, words and Makaton symbols and signs for all situations in the dental setting and can be used to help prepare the individual for their dental visit and to aid communication at the visit itself.

"Talking Mats" – (literally mats with pictures attached) was developed during a research project in 1998 by the SaLT team at Stirling University. They help people with communication difficulties to think about the issues discussed with them and to express their opinions. Since then, *Talking Mats* has been used with many people with and without communication difficulties both in the UK and abroad. People who have used *Talking Mats* have found it enjoyable and easy to use and recent research has proved it improves the quality and quantity of information gained. Examples of some of the resources available can be found at: **www.talkingmats.com**

- Talking Mats: A resource to enhance Communication

- Talking Mats™ and Learning Disability

3.5 Management of Specific Oral Complications

This section will deal with the management of some specific problems which can have a negative impact on oral health and/or the delivery of oral health care.

Self-Injurious Behaviour (SIB)

Oral self-mutilation or self-injurious behaviour may be seen in people with learning disabilities and is more common in children (Pattison, 1983). The most common types of oral SIB are self biting of hands, arms, lips, and tongue. The reasons for SIB are not clear and the pain of SIB does not seem to deter further injury (Carr, 1977). It can be linked to Cerebral Palsy, Autism, Tourettes, Lesch-Nyan Syndrome, or profound neuro-disability and can be the result of an exaggerated or abnormal oral reflex, habit, pain and/or frustration.

The oral injuries which are inflicted, can lead to infection, scarring and permanent damage (Fenton, 1982). Before treatment can be implemented, a full multidisciplinary assessment is required. This includes obtaining a detailed history of the SIB i.e. severity and frequency. It is important to rule out any dental and/or medical causes of the self-inflicted trauma, such as undiagnosed pain. The assessment should also include an evaluation of the patient's and carer's ability to co-operate with treatment for the SIB.

Treatment options are dependent on the cause and severity of the condition and whether short or long-term management is required. Most importantly, it will depend on the individual and their ability to cope with the recommended treatment. Various forms of treatment have been instituted in an attempt to prevent lip biting, and a number of treatments may need to be tried before the best option is found.

Treatment/management options can include the following:

1. Symptomatic relief

2. Reassurance for patients, parents and carers with monitoring of the situation

3. Distraction when SIB is observed

4. Pharmacological treatment e.g. prescription of Haloperidol, Diazepam and Carbamazepine

5. Behavioural psychology such as positive reinforcement to help modify behaviour

6. Construction of oral appliances to shield the tongue, cheeks and lips from injury such as hard acrylic or soft, vacuum moulded mouth guards, bite-raising appliances, splints, tongue stents and lip plumpers/bumpers

7. Extraction of specific anterior teeth, although this may transfer the SIB to another area of the mouth rather than resolve the behaviour

8. Orthognathic (jaw) surgery to create an open bite and prevent self injurious biting, may also result in moving the behaviour to another part of the mouth or another part of the body rather than resolving the issue

Drooling

Drooling is described as the involuntary loss of saliva (spit) from the mouth, persisting after age 4 (Finkelstein and Crysdale, 1992). It can manifest itself in childhood and adulthood and is a distressing and embarrassing condition as well as a social stigma.

Causes include:

- Impaired oral muscle control e.g. poor lip seal

- Decrease in frequency of spontaneous swallowing

- Difficulty in swallowing (dysphagia)

- Head forward posture (Hussain et al., 1988)

- Hypersecretion (excessive production) of saliva

Associated disorders:

Drooling is a characteristic of some conditions. For example:

- Dysphagia

- Cerebral palsy

- Parkinson's disease

- Multiple sclerosis

- Stroke

- Brain injury

Usually, drooling results from a combination of impaired oral muscle control, decreased frequency of or ability to swallow, and head forward posture rather than excessive saliva production. Drooling and dysphagia, complicated by difficulties with eating, drinking and swallowing, can have implications for health, safety and wellbeing. Among adults with learning disabilities, 40% of people with dysphagia experience recurrent respiratory tract infections (Department of Health, 2010a)

Assessment

Family and carers can be encouraged to keep a diary of frequency and severity of drooling. Severity can be classed as: mild (effects lips only), moderate (face and/or chin involved), severe (clothing becomes wet), profuse (saliva spreads to hands and objects). A diary can be used to record the drooling and thereby, assess the management approach required (Thomas-Stonell and Greenberg, 1988).

Management:

The management of drooling is not always easy and it may be necessary to try a number of strategies to achieve an improvement. Management strategies include:

- Oral motor approaches – sensory stimulation of the oral muscles by brushing , vibration or the use of dental appliances

- Body positioning and head support – to prevent a head down posture which contributes to poor saliva control

- Behavioural approaches - with reminders and/or rewards for behaviours likely to reduce drooling such as swallowing. For example, 'beeper brooches' have been used for people with Parkinson's disease to remind them to swallow regularly

- Medication - anticholinergics, commonly administered as transdermal patches. There have been some early studies showing success of botulinum toxin (Botox) injections (Lim et al., 2006)

- Surgery - Bilateral submandibular duct relocation with bilateral sublingual gland excision has been shown to be effective and safe in long-term follow-up (Lal and Hotaling, 2006)

Whatever strategies are employed, there is a balance to be found between reducing salivary flow and causing dry mouth which can, in turn, lead to discomfort and dental decay. Regular dental examination and extra preventive measures are mandatory for patients undergoing surgery and/or therapy that results in reduction of saliva.

Dry mouth (Xerostomia)

Dry mouth is a symptom of reduced or absent saliva flow in the mouth. Xerostomia is not a disease, but it may be a symptom or side effect of other conditions.

Common causes include:

- Medication - this is the most common cause of a dry mouth. A wide variety of drugs can cause it, including antidepressants, anticholinergics, antipsychotics, drugs (Bartels) for Parkinson's disease, diuretics and sedatives. People with multiple or chronic disease often have reduced salivary secretion. Both the likelihood and the degree of xerostomia increases when a number of drugs are taken concurrently (Griffiths and Boyle, 2005)

- Systemic diseases - such as Sjögrens syndrome, Parkinson's disease and psychotic illness such as schizophrenia can cause dry mouth

- Drug misuse

- Radiotherapy - for head and neck tumours can affect the salivary glands causing temporary or permanent xerostomia

- Mouth breathing – this can be a complicating factor in people with a learning disability

- Anxiety

Effects of dry mouth:

Saliva has a number of important functions including antimicrobial activity, mechanical cleansing, control of pH (acidity), removal of food debris from the oral cavity, lubrication of the oral cavity, remineralisation and maintaining the integrity of the oral mucosa (Bartels CL).

Individuals with xerostomia often complain of problems with eating, speaking, swallowing and wearing dentures. They may complain of taste disorders, a painful tongue and an increased need to drink water, especially at night (Bartels).

Xerostomia can lead to markedly increased dental caries (decay), dryness and fissuring of the lips, sore tongue, infection with oral candidiasis, and halitosis (bad breath) (Bartels CL).

Assessment:

Diagnosis and assessment is based on:

- Clinical history - changes in saliva flow, dryness at mealtimes and at night, and difficulty in swallowing

- Medical history - systemic disease, medications, radiotherapy, drug misuse

- Clinical examination - mucosa is dry and gloved fingers or the mouth mirror sticks to cheeks or lips, tongue is fissured, saliva is thick, stringy and/or frothy, teeth show a characteristic pattern of caries on the root surfaces, cusps and incisal edges

- Salivary flow tests can be employed to measure flow rate and gland activity

Management:

Ideally, management includes identification of the underlying cause and steps to minimize its dry mouth effect. However, for many individuals little can be done to alter the underlying cause and management will be symptomatic.

Symptomatic treatment typically includes:

- Increasing existing saliva flow - chewing sugar free gum or using saliva stimulating tablets/ pastilles

- Replacing saliva - with artificial saliva or gel or other lubricants

- Controlling/preventing complicating factors and development of dental decay through the three cornerstones of preventive dentistry for patients at high risk of developing caries i.e. delivery of fluoride, good oral hygiene and well balanced diet (low sugar/reduced frequency of sugar; particularly at night) (see Section 4).

If using saliva substitutes, care must be taken to choose the appropriate product, for example avoiding those with citric acid for people with natural teeth and porcine products for vegetarian, Jewish and Muslim individuals. (Griffiths and Boyle, 2005).

Tube (enteral) feeding

Tube (enteral) feeding refers to the use of gastrostomy (PEG), jejunostomy or nasogastric (NG) tubes to deliver artificial feeds due to nutritional needs, failure to thrive or impaired swallowing. This may be due to an inability to feed through the mouth following surgery, injury or tumour; or due to the need to protect the airway due to neurological conditions such as Cerebral Palsy, Huntingdons disease, Multiple Sclerosis or Motor Neurone Disease. Additionally, people who are tube fed have difficulty in protecting their airways due to lack of co-ordination of swallowing with breathing.

Lack of feeding by mouth results in reduced oral stimulus, subsequent changes in the saliva constituents, and calculus, which tends to build up more easily than usual.

Despite not taking food by mouth, it is important for carers and the dental team to work together to develop a robust oral hygiene package for the individual who is tube fed. This should take account of the training needs of the carer; the use of low foaming toothpastes to avoid aspiration; working to reduce 'oral defensiveness' (increased oral sensitivity) which may develop as a result of PEG feeding; and taking particular care when scaling to remove calculus as the airway is vulnerable. The use of a suction toothbrush can also be of benefit.

Oral stimulation (through tasters and other stimulation) is necessary to maintain a certain amount of salivary flow, without which dental caries, dryness and cracking of the lips, crusting of the tongue and a build up of calculus on the teeth, is likely to occur.

Tooth Wear

Tooth Wear is the loss of tooth surface, which is not caused by decay or by an injury. Typically, it falls into the three main categories of:

- Abrasion

- Attrition

- Erosion

Although three causes of tooth wear are clearly defined, tooth wear in any one individual is usually the result of more than one of the processes acting together.

Abrasion

Tooth abrasion is caused by mechanical behaviours such as aggressive tooth brushing. Abrasion is the wearing away of tooth surface caused by friction, for example as occurs when teeth are brushed too vigorously using a scrubbing style action. Long term use of a hard toothbrush can also cause the problem, resulting in a wedge or V-shaped groove on the buccal (cheek) surface of back teeth.

The wear of enamel and cementum (which protects the dentine surface of the root) can result in dentine sensitivity and dental pain. Management of the tooth wear is through changing brushing habits, techniques and/or appliances in accordance with advice from the dental team. The abraded areas can be repaired by bonding a tooth coloured filling over them. This is a relatively non-invasive dental technique but still requires a degree of patient co-operation.

Pica

Abrasion can also occur in the eating disorder Pica, a condition in which non-nutritive substances (e.g. coal, soil, pebbles, chalk, etc) are persistently eaten. The aetiology of pica is not understood but it occurs in a proportion of people with development and learning disability and autistic spectrum disorder. The dental team should consider Pica in the differential diagnosis when faced with an atypical pattern of tooth surface loss. The chewing of abrasive items leads to cupping and grooving of dentine and sharp enamel rims, in contrast to the smooth enamel seen in erosion. Also the wear facets do not match in the intercuspal position, as in attrition (Dougall and Fiske, 2008b). Restoration of tooth loss will be short-lived unless the underlying eating disorder can be managed. Close liaison with healthcare professionals is advocated prior to provision of dental treatment of people with this condition.

Attrition (tooth grinding)

Attrition is the mechanical wearing down of the biting and chewing surfaces of teeth. Tooth to tooth contact during chewing grinds down the surfaces so that the posterior teeth become flatter, and anterior teeth become shorter. This type of tooth wear also takes place normally as part of the ageing process.

Bruxism is the most common cause of non-age related attrition and is the non-functional, involuntary (or sometimes voluntary) clenching or grinding of teeth. Bruxism often leads to tooth wear and in severe cases to pulpal (nerve) damage and to dental pain and sepsis (Richmond et al., 1984). It can also cause unpleasant and, in some cases, unrelenting noise which may be the main reason why family and carers seek professional help on behalf of the individual with a learning disability. Bruxism can take place during waking hours but occurs more commonly during sleep. The individual who is bruxing is often unaware of the condition.

Suggested causes are:

- Psychological conditions such as sleep disorders, stress, drug misuse

- Malocclusion

- Neurological conditions such as brain injury, stroke and cerebral palsy

Whilst bruxism has been reported as more common in children with Down's Syndrome (DS) the findings are mixed. (Bell and Kaionis, 2002) report it as significantly more common than in the general population (59% and 8% respectively), while more recently, bruxism has been reported as no more common in children with DS than in those without it (Lopez-Perez et al., 2007, Buckley, 2007). There appears to be no evidence to indicate whether tooth wear and/or bruxism is a problem in adults with DS (Lewis et al., 2008).

Erosion

Tooth erosion is a non-bacterial chemical process caused by contact with acids, for example in foods and beverages. This can be as the result of gastro-oesophageal reflux disorder (GORD), or excessive vomiting, or from the consumption of acidic drinks and foods.

Dental erosion is the irreversible loss of dental hard tissue due to a chemical process not involving bacteria, and not directly associated with mechanical or traumatic factors, or with dental caries (Royal College of Surgeons, 2007). Essentially, it is the wearing away of tooth surface by an acid, which dissolves the enamel and the dentine. The two sources of acid in the mouth are dietary (extrinsic) and gastric (intrinsic).

Extrinsic acids

Foods and drinks with a high acid content include:

- Carbonated drinks - regular, diet and sports varieties

- Fruit squashes and fruit juices - a major cause of tooth erosion

- Citrus fruits such as oranges, lemons and grapefruit

- Fruit juices

- Pickles and vinegar

- Yoghurt

- Alcoholic drinks

Other extrinsic sources causing erosion are:

- Medications, such as Vitamin C and iron supplements

- Oral hygiene products such as acidic mouthwashes and saliva substitutes with a low pH

- Environmental contact with acids through industrial processes at work or leisure activities (e.g. swimming pools)

Intrinsic acids

Stomach acid in the mouth as a result of gastro-oesophageal reflux (due to sphincter incompetence, increased gastric pressure and increased gastric volume) and vomiting or rumination can dissolve tooth enamel and dentine.

Any condition that causes repetitive regurgitation or vomiting will result in the erosion of teeth, including:

- Gastro-oesophageal Reflux Disorder (GORD)

- Eating disorders such as anorexia nervosa, bulimia nervosa, binge eating disorder and Prader-Willi syndrome

- Hiatus Hernia

- Excessive consumption of alcohol

- Morning sickness in early pregnancy, although this is self-limiting

Gastro-oesophageal Reflux Disease (GORD)

In some cases reflux can be a secondary problem to another condition (Living with Reflux). Those conditions with recognised links to GORD include:

- Asthma – which can be misdiagnosed for reflux and vice versa

- Cerebral palsy (CP) - Many people with CP also have reflux, because CP affects the tone of the muscles including the lower oesophageal sphincter allowing the stomach contents to reflux into the oesophagus and mouth

- Cornelia de Lange syndrome

- Diabetes type 1 and 2, due to delayed gastric emptying

GORD can cause pain and may contribute to sleep disturbance, problem behaviour, anaemia, risk of oesophageal cancer and aspiration leading to recurrent bouts of pneumonia. (NHS Health Scotland, 2004) Whilst a Dutch study found that almost 50% of institutionalised people with moderate and severe learning disabilities had GORD (Bohmer et al., 1999) there are seemingly no UK-based data on the prevalence of GORD among people with learning disabilities (Department of Health, 2010a).

Prader-Willi syndrome

Prader-Willi syndrome (PWS) has the major characteristics of hyperphagia (appetite disorder), GORD, mild to moderate cognitive impairment, behaviour issues, and hypotonia (affecting motor skills and delaying speech). The major medical concern is morbid obesity due to hyperphagia associated with food foraging and obsession. The urge to eat is physiological, overwhelming and difficult to control.

The oral conditions associated with PWS in children and adults include hypoplastic or thin enamel, 'thick sticky saliva', and caries, which can be rampant. In adults, progressive tooth wear has also been described (Dougall and Fiske, 2008b). The increased caries risk is attributed to high frequency intake of sugars and the altered viscosity and amount of saliva. The need for early dental consultation and a robust preventive programme is very important in managing the oral health of people with PWS.

Recognition of erosion

The characteristic pattern of tooth surface destruction in erosion means that the dental team may be the first to notice the problem. The palatal (back surfaces) of the maxillary (upper) incisors (front teeth) are often the first to be affected. However, an indication of the source of the acid can be given by the pattern of tooth surface loss with gastric acid, often affecting the palatal surfaces of upper molars. The areas of erosion appear as light yellow patches on the teeth, indicating that the enamel has been dissolved or eroded and the sensitive dentine (usually protected by the enamel) has been exposed. Dentinal exposure is likely to result in pain from sweet, hot and cold food and drinks. In contrast to attrition, tooth substance only is affected, often leaving amalgam fillings proud of the tooth contour.

Assessment of tooth wear

Whether the cause of tooth wear is due to abrasion, attrition (bruxism) or erosion, it is important to establish:

- *The degree of tooth wear that has already occurred* – this is usually rated according to the severity of dental surface tooth loss and the number of teeth affected. Severity increases from enamel wear (such as loss of cuspal contours and flattening of teeth) to exposure of dentine (sometimes resulting in sensitivity) and pulpal exposure or nerve involvement (which can result in pain and infection)

- *The rate of tooth wear* – this is usually assessed using serial study models taken over a period of time, allowing easy comparison of the dental status during this period. This approach requires taking impressions of the mouth and may be limited by patient co-operation. Visual assessment using a tooth wear index may be an appropriate substitute procedure for recording the rate of toothwear. A simple index records the following by each sextant:

  - 0 none

  - 1 into enamel

  - 2 into dentine

  - 3 into pulp

Management of Attrition (Bruxism) and Erosion

Attrition / Bruxism

The management of bruxism is not always easy. Its effects can be reduced and sometimes remedied by the use of a soft plastic or a hard acrylic bite guard, which is usually worn during sleep. Co-operation is required to have the impressions taken to make the bite guard and perseverance is required to get accustomed to wearing it and sleeping with it in place.

Botox injections into the masseter muscles have been used to control bruxism through reduced muscle activity (El Maaytah et al., 2006). Oral motor approaches using biofeedback devices with tastes or alarms have also been used. However, much of the evidence for these techniques has been reviewed as weak and there is a lack of robust trials in the management of bruxism (Lobbezoo et al., 2008).

The damage to teeth and sensitivity to hot and cold can be managed by bonding tooth coloured filling material over the damaged surfaces or provision of crowns. Bonding is a relatively non-invasive dental technique that requires a degree of patient co-operation. Construction of crowns is a more complex procedure requiring good patient co-operation for all stages of the procedure.

Erosion

Management of erosion requires:

- Identification and management of any intrinsic cause through consultation with the patient's doctor and referral for specialist care if necessary

- Identification and elimination/control of extrinsic causes through dietary analysis and modification

- Management of dentine sensitivity

- Restoration of lost tooth tissue through use of bonded tooth coloured filling material over the damaged surfaces or crowns

- Appropriate oral hygiene measures and advice

Dietary and oral hygiene advice to minimise erosion includes the following:

- Reducing or eliminating the intake of carbonated drinks

- Reducing the frequency of intake of acidic fruits and drinks

- Including these foods and drinks as part of the regular meals to dilute the acidity of the food in the mouth and limit the time it is in contact with the teeth

- Reducing retention of acidic foods and drinks inside the mouth

- Chewing sugar-free gum, sucking a sugar-free lozenge or eating a piece of cheese after an acidic meal, to encourage saliva production and protect enamel

- Delay brushing of teeth for at least one hour after consuming acidic food or drink

- Using a medium/soft toothbrush

- Using a low-abrasion, low-acidity, high-fluoride, anti-hypersensitivity dentifrice (toothpaste)

3.6 Use of Conscious Sedation for People with a Learning Disability

Introduction

Conscious sedation is described as: 'A technique in which the use of a drug or drugs produces a state of depression of the central nervous system enabling treatment to be carried out, but during which verbal contact with the patient is maintained throughout the period of sedation' (Scottish Dental Clinical Effectiveness Programme, 2006). The drugs and techniques used to provide conscious sedation for dental treatment should carry a margin of safety wide enough to render loss of consciousness unlikely.

Conscious sedation is used in dentistry as an adjunct to patient management for people who are unable to cope with conventional dental treatment and to avoid recourse to the use of general anaesthesia. Indications for its use include:

- Dental anxiety and phobia

- Prolonged or traumatic dental procedures

- Medical conditions potentially aggravated by stress

- Conditions affecting the patient's ability to cooperate

The aims of sedation include reducing fear and anxiety, augmenting pain control, minimising movement and increasing safety. The importance of each of these aims will vary depending on the nature of the procedure and the characteristics of the individual patient.

In all situations, it is of fundamental importance that the level of sedation must be such that the patient remains conscious, and is able to both understand and respond to verbal commands. If a patient is unable to respond to verbal contact when fully conscious, the normal method of communicating with them must be maintained.

The definition describes the state of conscious sedation, and does not attempt to prescribe how it is achieved. Specifically, it is acknowledged that a number of techniques involving the use of one or more drugs administered via different routes will fulfill this definition provided that there is an adequate margin of safety. The majority of conscious sedation undertaken in dentistry involves the use of a single drug, either nitrous oxide or midazolam. Nitrous oxide is inhaled through a nasal mask and midazolam is administered mostly via intravenous injection. These techniques are considered to be '*basic*' techniques and are the basis of undergraduate training for conscious sedation in dentistry. Conscious sedation involving drugs other than intravenous midazolam or nitrous oxide alone are referred to as '*advanced*' (previously referred to as 'alternative') techniques. How to use advanced conscious sedation techniques is not part of dental undergraduate training and is considered to require further training to achieve the required level of competence and experience.

People with a learning disability

Conscious sedation can be useful in the provision of dental treatment for both adults and children with a learning disability. However, it should be provided only by those who are experienced in sedating people with additional needs and where the appropriate equipment and facilities are available. The Society for the Advancement of Anaesthesia in Dentistry (SAAD, 2009) produced a toolkit which allows providers, commissioners and regulators of services to assess the quality of their conscious sedation services and highlight any areas which need attention.

The patient's response to their environment and to interventions may vary. It is influenced by factors such as their degree of cognition, ability to cooperate, whether they have dental pain, and the influence of their medical history on the proposed treatment. Corresponding adaptations to treatment protocols may be required. For example, the standard practice of pre-operative recording of physiological data (e.g. blood pressure and oxygen saturation) and/or oral examination may not always be possible. In such cases, reasons for deviating from standard practice should be recorded in the patient record.

It can be difficult to judge the level of sedation in patients who are unable to respond well to verbal communication. In the case of patients who are unable to respond to verbal contact when fully conscious, it is essential that the normal method of communicating with them is known and is maintained throughout the episode of sedation (Scottish Dental Clinical Effectiveness Programme, 2006)

The decision to use conscious sedation in the care of people with learning disabilities is influenced by a number of factors, including:

- Age

- Medical condition and medication

- Cultural acceptance of sedation

- Behaviour management problems

- Support from family and/or carers

- Experience and training of the dental team

• The appropriate use of different drugs and techniques either in the primary or hospital dental service

Quality assurance in delivery of safe patient care is essential and development of integrated referral centres providing an extended range of techniques, including alternative techniques, based on local needs, is recommended. This would allow patients with a learning disability to receive appropriate and expert management for conscious sedation techniques (Royal College of Anaesthetists, 2007).

Children and young people:

A Cochrane systematic review (Matharu and Ashley, 2006) provides evidence for a variety of conscious sedation techniques that have been used successfully for children in a manner that is safe and effective. The review did not reach a definitive conclusion about which drug or method of conscious sedation is the most effective.

The decision of which technique and/or drug to use will depend on a combination of those factors listed above and clinical guidelines. A recent National Institute of Clinical Excellence (NICE, 2010) Clinical Guideline for sedation in infants, children and young people under 19 years, incorporates a series of recommendations for healthcare professionals including nurses, anaesthetists, doctors and dentists. Key recommendations include:

• Treatment and care should take into account patients' needs and preferences.

• Children and young people undergoing sedation and their parents and carers

• should have the opportunity to make informed decisions about their care and

• treatment, in partnership with their healthcare professionals

• Where patients do not have the capacity to make decisions, healthcare professionals should follow the Department of Health's advice on consent (available from **www. dh.gov.uk/consent**) and the code of practice that accompanies the Mental Capacity Act (summary available from **www.publicguardian.gov.uk**). In Wales, healthcare professionals should follow advice on consent from the Welsh Assembly Government (available from **www.wales. nhs.uk/consent**). If the patient is under 16, healthcare professionals should follow the guidelines in 'Seeking consent: working with children' (available from **www.dh.gov.uk/ consent**).

• The child or young person (and their parents or carers) should be offered verbal and written information about the proposed sedation technique, the alternatives to sedation and associated risks and benefits

• Trained healthcare professionals should carry out pre-sedation assessments and document the results and any variation in practice in the patient's healthcare record

• Continuous monitoring of the child or young person should be carried out throughout the sedation, ensuring that the data is clearly documented in the patient's healthcare record

• Healthcare professionals delivering sedation should have documented up-to-date evidence of competency and should ensure they update their knowledge and skills through programmes designed for continuing professional development

The guideline also focuses on the need to ensure people aged under 19 and their families are prepared psychologically for sedation. It stresses the importance of good communication between healthcare professionals and patients, pointing out that it should be supported by evidence-based written information tailored to the patient's needs. Treatment, care and the information patients are given about it should be culturally appropriate and accessible to people with additional needs such as physical, sensory or learning disability, and to people who do not speak or read English.

Care of young people in transition between paediatric and adult services should be planned and managed according to the best practice guidance described in 'Transition: getting it right for young people' (Department of Health, 2006) available from **www.dh.gov.uk** .

(NICE Guidance - Sedation in Children and Young People, 2010)

Adults and Older People

As with children and young people a variety of conscious sedation techniques have been used successfully for adults and older people without any definitive conclusion about which drug or method of conscious sedation is the most effective. Additionally, the same principles for the delivery of safe and effective conscious sedation apply for adults and older people as apply for children and young people.

A number of seminal documents that set out the standards for conscious sedation in dentistry (Dental Sedation Teachers' Group, 2005) (Scottish Dental Clinical Effectiveness Programme, 2006; *Conscious Sedation in Dentistry*); (Standing Committee on Sedation for Dentistry, 2007– *Standards for Conscious Sedation in Dentistry; alternative techniques*), (Department of Health and Faculty of General Dental Practice, 2007 - *Guidelines for the Appointment of Dentists with a Special Interest in Conscious Sedation); and (SAAD, 2009 Standardised Evaluation of Conscious Sedation Practice for Dentistry in the UK*).

The Intercollegiate Advisory Committee for Sedation in Dentistry is currently developing guidance for training in Advanced Conscious Sedation Techniques in Dentistry. All of the above stress the importance that healthcare professionals who deliver sedation must have appropriate training, to ensure that their knowledge and skills are kept up to date through continuing professional development.

3.7 Use of General Anaesthesia for People with a Learning Disability

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 (Nunn et al., 1995). In 2009, the British Society for Disability & Oral Health published a professional consensus statement for general anaesthesia in Special Care Dentistry and the reader is referred to this document for a more comprehensive account of current professional opinion in this complex field (British Society for Disability and Oral Health, 2009b)**.**

Indications for General Anaesthesia

A clear inability to co-operate with the provision of dental care using other patient management techniques including sedation (or contraindications to the use of sedation).

Pre-operative Assessment

Systematic assessment of patients with additional needs reduces the indiscriminate use of general anaesthesia and minimises complications, as well as the need for further interventions (Limeres Posse et al., 2003).

Waiting lists for pre-operative assessment must be within nationally and locally agreed standards for waiting times for assessment for surgery and be sensitive to any additional needs the patient may have, as should the venue and style of the pre-assessment (The Disability Discrimination Act, 1995, 2005). It should be conducted in a venue and with a style which is sensitive to their needs.

Pre-operative dental assessment for patients requiring Special Care Dentistry with additional needs should, where at all possible, be undertaken by the dental surgeon carrying out the treatment. A second opinion should be readily obtainable if necessary, as should other specialist dental and medical input. Further assistance in patient assessment and management should also be arranged where required from paramedical (e.g. physiotherapy) and nursing staff.

All patients should be seen by an anaesthetist before undergoing an operation that requires the service of an anaesthetist (Association of Anaesthetists of Great Britain and Ireland, 2001). The anaesthetist must be a medically qualified anaesthetist on the specialist register held by the General Medical Council, or be a trainee working under supervision as part of a Royal College of Anaesthetists' approved training programme, or be a non-consultant NHS career grade doctor working under the supervision of a named consultant anaesthetist (Department of Health, 2000a, General Dental Council, 2005b). In addition the anaesthetist should have an understanding of Special Care Dentistry (JACSCD, 2003) and be empathic towards any additional needs of the patient.

The likely requirement for any special anaesthetic equipment, for example that is required for endoscopic intubation, should be determined and recorded by the anaesthetist at the pre-assessment.

A full dental, medical, social and if required, a family history should be recorded as well as, if possible and where indicated, an oral and physical examination. There should be systems in place to implement the local obesity strategy (National Institute for Health and Clinical Excellence, 2006). Facilities for radiographs and any other special tests required pre-operatively will also need to be available (NHS Modernisation Agency, 2003, NHS Modernisation Agency, 2002, National Institute for Clinical Excellence, 2003).

Patients who are not competent to give or withhold consent should be accompanied by a next of kin and/or an immediate carer (preferably a care manager or key worker) who has knowledge of the patient's medical history and any current medication and with whom, in addition, treatment options can be discussed in accordance with current UK legislation and guidance on consent, (*The Mental Capacity Act, 2005 and The Adults with Incapacity (Scotland) Act 2000, Department of Health 2002).* (Good practice in consent implementation guide: consent to examination or treatment. London, *Department of Health 2002*).

There should be an opportunity to discuss the potential need for use of pre-medication and Clinical Holding during induction of anaesthesia, as well as the need for any additional requirements, for example a hoist and sling for patient transfer.

Issues of transport, the need for the patient to be escorted, and the possibility of post-operative admission as well as aftercare at home, will also need to be addressed.

It is important to be clear about the oral health objectives and future dental treatment for patients, and the opportunity should be taken to discuss the long-term care plan with the relatives and carers. This is of particular relevance to preventive measures and exploring ways of improving compliance with diet and oral hygiene instruction, when necessary.

Emphasis should be placed on practical solutions to avoid the need for repeated general anaesthetics.

Simultaneous, non-dental investigations/interventions may be possible under anaesthesia. This approach is to be encouraged in the best interests of the patient but will require careful planning and an appropriate consent procedure and liaison with other Health Care Professionals and specialists as required.

Verbal and printed instructions should be given to include the following:

• Pre-operative fasting advice
• Any medication that should be administered prior to admission
• Information on Clinical Holding, in case it may be required
• Details about escorts and transport
• Time and venue for admission for treatment
• Items that should be brought along with the patient (loose clothing, medicines etc)
• Advice about analgesia
• Post-operative care
• Contact numbers for advice about surgery and anaesthesia as well as post-operative complications

Admission

As stated earlier, waiting lists from pre-operative assessment to admission for treatment must be within nationally and locally agreed standards for waiting times for admission to surgery, as well as being sensitive to any additional needs the patient may have.

The accommodation for day and in-patient care must:

• be accessible for people with disabilities
• be sensitive to the needs of patients with disabilities
• be consistent with patient confidentiality
• be as far as possible, non-anxiety provoking for the patient
• ensure that wherever possible, patients exhibiting distressed behaviour, do not disturb other patients

• be able to accommodate a carer

Special equipment, for example patient wheelchairs, transfer devices, including hoists and theatre trolleys must be available, and staff fully trained in their use in accordance with national and local manual handling regulations.

The admissions team will include the dental surgeons, anaesthetist, nursing staff and administrative staff. In addition, there may be occasions when the patient is admitted under the care of a medical and/or mental health team in view of a significant systemic and/or mental health disorder.

On arrival, the patient should be admitted into the ward or unit. The following should be checked and recorded:

• The patient's escort is present and transport home has been arranged

• Fasting instructions have been followed

• Medical history and medication list is checked and any changes noted

• All medication has been taken as recommended at the assessment visit

• All radiographs and reports are available

• Pre-operative investigations have been carried out and reports are available

• Where indicated, appropriate thromboembolic prophylaxis to avoid deep vein thrombosis has been arranged, (e.g. support stockings fitted) (National Institute for Clinical Excellence, 2010)

• The patient and/or carer have the opportunity to ask questions and clarify details

• Patient observations including (if possible in view of patient's disability) blood pressure, height, weight and BMI

• A record of a valid, signed consent procedure for the dental treatment and the general anaesthetic

Treatment

The accommodation and equipment for the surgery/treatment should include an operating room, with full lighting (Department of Health, 2002) and be large enough to accommodate the patient and all necessary staff (Cardiff and Vale Trust, 2005). In addition to anaesthetic equipment and a range of monitoring equipment there must be equipment and drugs needed for resuscitation that is immediately accessible (Royal College of Anaesthetists, 1999). Zoning of areas to provide clean and dirty utilities is essential (British Dental Association, 2003). (Department of Health, 2009b) (Health Technical memorandum 01-05, Decontamination in primary care dental practices, *Department of Health* 2008.)

Where investigations were not possible at initial assessment as a result of the patient's disability, there must be a facility for tests to be carried out in theatre, including provision for intra- and extra-oral radiographs with viewing screens directly visible to the surgeon.

The dental team must comprise of the following:

• A dentist with appropriate training and experience in Special Care Dentistry. Second opinions are advisable where examination and treatment planning is not possible pre-operatively (Department of Health, 2001, The Mental Capacity Act, 2005, Adults with Incapacity (Scotland) Act, 2000, Department of Health : Good Practice in Consent implementation guide 2002). This can be achieved by the presence of two experienced operators

• Appropriately trained and competent, dedicated nursing assistance

• Local access to specialist opinion/assistance for example, maxillo-facial surgery and restorative dentistry if required

The anaesthetic team must comprise of:

• An anaesthetist who fulfils the requirements as delineated above

• A dedicated anaesthetic assistant trained to nationally agreed standards (Association of Anaesthetists of Great Britain and Ireland, 2005)

Post-operative care

The anaesthetist must formally hand over care of the patient to a recovery room nurse or other appropriately trained member of staff (Association of Anaesthetists of Great Britain and Ireland, 2002).

The dentist should provide recovery staff with information regarding the dental procedures undertaken and any precautions required, including:

- Site and type of local anaesthetics used, including anticipated duration of action

- Site and types of fillings placed, especially those which may not have fully set

- Site and type of dental extractions (surgery, sutures etc) and of any dental/surgical packs

- Instructions for further pain relief

All patients must receive verbal and written instructions on discharge. These instructions should be given in the presence of the responsible person who is to escort and care for the patient. They should be warned of any symptoms that they might experience during the first 24 post-operative hours. Suitable post-operative medication (e.g. analgesics, antibiotics, mouthwash) may be prescribed if thought necessary. Specific instructions regarding mouth care after surgery should be given by a dentist. If sutures have been placed, guidance should be given as to the type of suture material used and how, if necessary, they will be removed. This should include any specific instructions relating to the surgical procedure. The patient should be advised not to drink alcohol, operate machinery or cook until at least the following day. Although it is generally recommended that adults should not drive for 48 hours (Royal College of Surgeons of England, 1992), recent research suggests that, from an anaesthetic point of view, avoiding driving for 24 hours is sufficient (Sinclair et al., 2003). In the event of a problem, the patient/carer must know where help or advice can be found. A list of contact telephone numbers should be supplied. If a review appointment is required, information regarding this is given prior to discharge.

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 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

B

- The consumption of sugary foods and drinks should be limited to meal times

- Cariogenic snacks should be avoided between meals

- Collaboration between dentists and dieticians will ensure that appropriate preventative 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

- Prolonged use of feeding bottles should be avoided

- Fruit flavoured sugar containing drinks should be limited at 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

Use of Fluoride

A

- Brushing with a family Fluoride toothpaste should be initiated as the first tooth erupts

- Children under the age of 3 years should only use a smear of toothpaste 1000ppm

- Children aged 3-6 years with an impairment or disability, should use a pea sized amount of 1350ppm

- Children aged 7 plus years should be encouraged to use 1350-1500ppm fluoride

A

- Children at higher risk, aged 10 years and above, can use toothpaste containing 2800ppm fluoride
- Direct supervision by an adult is advisable
- Parents should be fully involved in the decision to supplement fluoride levels
- The risks and benefits should be clearly explained so that parents can make an informed choice
- Professionally applied topical fluoride should be biannual

C

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

C

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

C

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. 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

C

- Professionals should collaborate to identify children with learning disabilities in mainstream and special education centres and refer to the appropriate oral healthcare services

Initial Visit

C

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

Regular Attendance

C

- Regular visits and reviews should be established 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

C

- 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 dental mobile units in mainstream and special schools should be explored where appropriate

Fissure Sealants

C

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

C ## 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

C ## 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 for the dental team 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

C ## Orthodontics

- Refer early with comprehensive information

- Obtain an orthodontic opinion before arranging treatment under a general anaethetic

- Treatment plans should take into account child compliance

- Avoid extracting permanent teeth until co-operation and oral hygiene are adequate

3.2 The Transition Stage

Oral Health Education and Promotion **C**

- Oral health education programmes should be developed that address the needs of individuals and carers (personal and 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 **C**

- 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 **C**

- Dietary advice for all people with learning disabilities should be made within the context of healthy eating policies

- Carers and health professionals should be provided with training to promote healthy eating and its effect on oral health

- Policies should be developed to ensure referral to and advice from the dental team to instigate appropriate prevention techniques

C 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
- 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

C Oral Assessment and Care Planning

- Everyone should have a regular oral assessment
- The frequency of the 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

C 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

C Treatment and Care

- Treatment and care should be offered based on the needs of the individual
- 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
- 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 use of mobile facilities

C 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

C 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

C ## 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 Salaried Dental Services 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

C
- 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

C ## Drooling
- A multidisciplinary team should make an individual assessment
- Techniques designed to improve posture should be implemented
- Treatment should be started with non-pharmacological and non-surgical methods
- There should be careful monitoring for oral complications if surgical or pharmacological treatment is carried out

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

Erosion
B
- Patients should be advised to use Fluoride mouthwashes, unless there are swallowing difficulties
- Toothpaste which is low in abrasion, low-acidity, high-Fluoride and anti-hypersensitivity, should be used regularly
- Brushing should be delayed for at least one hour after consuming acidic food or drink
- Professional application of fluoride varnish is advised
- Dentine bonding agents may be of value
- Referral to an appropriate dental specialist may be advised
- Reduce or eliminate intake of carbonated and acidic drinks and acidic fruits, or include as part of regular meal times
- Chew sugar-free gum, suck a sugar-free lozenge or eat cheese after an acidic meal

Dry Mouth
C
- Saliva replacements may be helpful
- The use of sugar-free chewing gum and sugar-free fluids is advised
- The mouth should be examined regularly
- Fluoride rinses or high fluoride containing toothpastes are advised
- Referral to an appropriate dental specialist may be required

Self Injurious Behaviour
C
- All dental causes should be eliminated
- Construction of mouth guards or other oral appliances should be considered
- Distraction and behavioural psychology is a useful management option

C

Feeding Problems

- Individual assessment should be carried out

- Good oral hygiene should be promoted

- An intensive regime should be followed to prevent oral disease

- A multi professional approach is advised

- A low foaming toothpaste is recommended

- The use of a suction toothbrush can be of benefit

- Therapy should be carried out to try and reduce oral defensiveness

3.6 Use of Sedation for People with Learning Disabilities

C

- Each person should be assessed individually

- Appropriate facilities and equipment should be available

- The whole dental team should have appropriate training and updates

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

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- General anaesthesia should be the last choice for treatment

- Collaborative work should be undertaken with professional colleagues to minimise the number of general anaesthetics required

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 (Warren et al., 2000) 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

- Toothbrush for infants 0-2years

- Small child's toothbrush Over 2 years

- Child's toothbrush 7 years to Adult

Toothpaste

Always use fluoride containing toothpaste. Non-foaming toothpastes are available (e.g. for people fed by tube or those who are 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 (Burtner et al., 1996, Stiefel et al., 1995).

Chlorhexidine gel (1%) applied at home daily, along with 6-monthly professional prophylaxis may be as effective and efficient a means of maintaining periodontal health in individuals with Down Syndrome. Chlorhexidine varnish (40%) applied 6-monthly may offer some additional benefit (Freedman et al, 2011).

Denture Care

- Dentures should be removed from the mouth for cleaning.

- Hold the denture over a bowl of water as this will 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, but if they contain a metal structure, they should be soaked in an alkaline peroxide solution for 30 minutes. The dentures should be rinsed, brushed and rinsed again, before storing dry overnight (Wilks, 1997)

- 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 still 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 gloves which are latex free.

4.2 Overcoming Specific Problems in Oral Care

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

Aids to toothbrushing: Finger shields have a small head of soft latex tufts which 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. NB: care must be taken to avoid the risk of inhalation or swallowing.

Strong tongue thrust: A mobile tongue or tight lip can 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 (Wilks, 1997). Using a smaller toothbrush can be beneficial.

Reduction in oral sensitivity: Some children and adults with an impairment or disability, may require a considerable amount of oral de-sensitisation. Various appliances are recommended by occupational therapists and speech and language therapists for this procedure. However, they do not remove plaque if used for cleansing.

Reduced co-operation: 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 gently hold and support the hands to prevent the person from pulling the toothbrush out of their mouth (Journal of the American Association of Hospital Dentists 1993).

Problems with Oral Clearance: Impaired oral clearance can lead to an increased risk of dental decay (Gabre, 2009). Training programmes which stimulate oral motor function and oral sensory perception can improve oral clearance.

4.3 General Dental Advice for Service Users

Diet

- Restrict sugar containing foods and drinks wherever possible

- Between meals, avoid snacks and drinks that contain sugar, including those which are carbonated or fruit flavoured

- Choose bread, toast, naan bread, chapatti, poppadums, cheese, fresh fruit and vegetables instead. Drinks could be milk, water, tea or coffee (without sugar) or those which are acknowledged as "tooth kind"

- Always ask your doctor or chemist for sugar-free medicines

- Moderation and infrequent consumption of food and drinks which contain sugar, is a good regime to follow

- Diluting drinks with water or use of a straw can also help

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 which contains fluoride

- If your gums bleed – keep brushing – gently and thoroughly

- If your gums continue to bleed for more than 2 days, contact your dentist

Visiting the Dentist

- Visit your dentist at least twice a year (following NICE Guideline for Recall and after the dentist has assessed the risk of oral disease)

- Tell the dentist if you are having any trouble with your mouth

- Find a dentist you can talk to – ask your family or friends for recommendations

- 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 and intrusive procedure and can be frightening

- Choose a suitable time, when carer and person are relaxed

- Professional carers should wear latex free gloves for cross infection control when assisting with toothbrushing

- Gloves should be changed for each individual

- Partial dentures should be removed before cleaning natural teeth

- Work in a good light, e.g. use a desk lamp if necessary

- 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. Consider working with two carers for toothbrushing

- Stand behind the person, slightly to one side. This position may have to be varied, according to what is comfortable for the client and carer

- Toothbrushes can be adapted in many ways for those who have limited manual dexterity. Consider using alternative toothbrushes, e.g. 'Superbrush' or 'Collis Curve' and discuss with your dentist first

- A study carried out looking at the effectiveness of different toothbrushes for people with special needs, found that a 3 headed brush performed best (Kaschke and Zeller 2005)

- Gently draw back the cheek and lips with 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 cooperation is limited, brush different areas of the mouth each day, recording what has been achieved at each session

- 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, they still need cleaning every day

- Do not stop brushing if you notice gums bleeding; leaving plaque behind on the teeth and gums will only increase gum problems and exacerbate the problem

- Help the person to rinse out with water or clean around with a damp swab. Encourage spitting out but not rinsing away the fluoride toothpaste

- Straws can be useful for some people, to help people rinse their mouth

- 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

- Consider the use of disclosing tablets on the teeth to check the effectiveness of toothbrushing and in removal of plaque

- Use a chart to record when teeth are brushed and when it has not been possible

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

Evaluation of a long-term oral health programme by carers of children and adults with intellectual disabilities undertaken in 3 French centres, showed an increase in frequency of daily brushing by the carers (Faulks and Hennequin, 2008). There was also an increase in the number of carers finding the brushing easy, and those able to brush the posterior, as well as the anterior teeth. The results emphasised the need for ongoing training for carers and the dental profession. It also highlighted the need for a means of measuring the impact of such interventions on these care providers.

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 (Changing Carers' Practices: A Policy for Oral Hygiene: British Society for Disability and Oral Health, 1999). 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.

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 to 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 (Kaschke et al 2005).

Example of Good Practice:
An Oral Health Care Plan

(Community/Salaried Dental Services Solihull HealthCare NHS Trust and Surrey Community Health)

Name					
Problem identified in conjunction with dental staff	Goal	Specific Action, planning, methods	Materials required	Staff	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.

C 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 (Nutritional Task Force, 1994)

- Healthy snacks should be encouraged as an alternative (Nutritional Task Force, 1994)

- Sugar-free medicines should be used whenever possible (Nutritional Task Force, 1994)

- The consumption of fizzy drinks and citrus fruit should be limited to mealtimes (Nutritional Task Force, 1994)

- 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

- Carers and the dental profession should undergo ongoing training programmes related to oral health

- A three headed toothbrush can be very effective and efficient in achieving good oral health

- Straws can be useful for helping people to rinse out their mouths

- Chlorhexidine gel (1%) may be effective in reducing periodontal disease, if applied at home daily, plus 6-monthly professional prophylaxis

5

Commissioning of Oral Health Care Services for People with Learning Disabilities

5.1 Introduction

Commissioning of Oral Healthcare Services for people of all ages with a learning disability is necessary to prevent oral disease through oral health promotion and education and to provide them with professional advice and treatment. The scientific background and recommendations for oral health promotion are contained in the policy document published by the British Association for the Study of Community Dentistry in April 2000. Primary Care Trusts in England, and equivalent commissioning and planning organizations within the other UK countries will need to commission comprehensive and appropriate oral healthcare services for this group of the population that include services and specialist care, as identified by their local needs assessment. This chapter is based on the philosophy of the Department of Health's World Class Commissioning advice (British Society for Disability and Oral Health, 2009b) and the commissioning section of the British Society for Disability and Oral Health's Guidelines for Domiciliary Oral Health Care Services (British Society for Disability and Oral Health, 2009a). Whilst these documents were written with the English commissioning system in mind, the principles embedded in these documents should be considered within planning and commissioning services for the other UK countries.

5.2 Commissioning

Commissioning oral healthcare services for people with a learning disability should be set in the context and current agenda of equality, diversity and human rights in both health and social care and reducing healthcare inequalities through personalisation, consultation and partnership working. Thus, it is fitting that the *'Our Vision for Primary and Community Care'* (Department of Health, 2008c) draws together the main conclusion of *'The Next Stage Review' (Department of Health, 2008a)* for community-based NHS services (including primary dental care), and sets out an agenda based on the following four key areas:

- Shaping services around people's needs and views
- Promoting healthy lives and tackling health inequalities
- Continuing improving quality
- Ensuring change is led locally

From April 2006, the Government of England conferred a statutory responsibility on Primary Care Trusts (PCTs) for commissioning services, devolved commissioning budgets and introduced a system of local contracts with dental providers (Department of Health, 2008c). Out of these reforms grew commissioning for *'additional and specialist services'*, including dental services for people with a learning disability.

The 2009 – 10 Operating Framework (Department of Health, 2008b) clarifies the priority for PCTs to develop NHS dental services to meet the local needs for access, quality of care and oral health in order to provide services to anyone who seeks help in accessing them. The key elements for a successful dental commissioning strategy that will enable this to be delivered include:

- Accessing local needs

- Mapping current services

- Developing a strategic commissioning plan

- Delivering improvements through:

  – transparent use of performance information

  – supporting quality improvement

  – providing information for patients and public

  – assuring minimum standards

  – promoting patient choice

  – developing the market, and

  – commissioning new and or additional capacity

- Improving premises and estates, including domiciliary equipment

- Top-level (e.g. Board) ownership

- A systematic approach to monitoring for performance (Department of Health, 2008b)

Taking into account the proposed NHS reforms for England (Department of Health, 2011), it is likely that PCTs will be abolished from April 2013. As a main aim of the reforms is to modernise and strengthen commissioning of services, the robust principles set out in this section will remain credible.

5.3 World Class Commissioning

Effective commissioning, which is essential to improving the quality of primary care services, has led to the development of the World class commissioning (WCC) programme in England (Department of Health, 2008c). WCC requires all PCTs to develop their five year strategic plan, which sets out the PCT vision, its priorities and how these will be delivered. It includes the high level *'patient offer'*, which sets out what the PCT is accountable for delivering to its local community.

Strategic plans will explain:

- What services will be provided

- Where they will be available, and

- Who will provide them?

PCTs are also required to prepare an annual operating plan, setting out how it will implement its strategy in the coming year. Both the

strategic and operating plans should address how primary care services will be improved and, where there is a need, this should include oral healthcare services for people with a learning disability.

The annual cycle of this WCC assurance holds PCTs to account. At the same time, PCTs need to be able to provide clear assurance that the services being accessed provide safe and effective care and good patient experience, in line with the objectives of *High Quality Care for All (Department of Health, 2008a)*. The distinctive features of commissioning primary dental care are set out in *'Primary care and Community Services: Improving dental access, quality and oral health'* (British Society for Disability and Oral Health, 2009a)

5.4 Mapping the Baseline

In order to make improvements to primary care services, including oral health care for people with a learning disability, a baseline needs to be established. There are three key stages to mapping the baseline:

1. Assessing needs

2. Mapping existing services

3. Identifying what needs to change

These key areas allow for identification of:

1. Services gaps

2. Potential for redesigning services

3. Level of resources required

Stage 1 Assessing local needs – this is usually done through a Joint Strategic Needs Assessment (JSNA) which entails having a clear understanding of the diversity of the local population (including associated patterns of oral health and service demand); specific communities with unmet or comparatively greater health needs (such as children, adolescents and adults with learning disability including older people in residential care or confined to home); and how these needs compare with similar populations elsewhere, through benchmarking (British Society for Disability and Oral Health, 2009a). Obtaining patient feedback and assessing levels of patient satisfaction are essential to the commissioning process.

Assessing oral health needs and assessing demand for dental services are also essential elements of the process. *'Valuing People's Oral Health – best practice guidance for improving oral health in disabled children and adults'* (Department of Health, 2007) contains useful information on needs assessment. Assessing demand for dental services is not straightforward. The current access indicator, of the number of people using the services within a two year period, is not an accurate proxy for levels of unmet need or demand. It is suggested that the simplest way of gauging unmet demand is to set up a well-publicised dental access helpline for both people seeking urgent care and those seeking a regular NHS dentist, monitor the nature of the requested needs and the ability to offer services to meet them (Department of Health, 2009b).

It is recognised that this approach needs to be sensitive to the needs of easily overlooked groups, such as older people who may need domiciliary care and people with disabilities (British Society for Disability and Oral Health, 2009a). Effective marketing and community engagement are required to promote awareness of how to access services amongst these groups and their families and carers. For example for people with a learning disability this may include targeting local community learning disability teams, local learning disability support organisations (including local branches of MENCAP), and facilities such as day centres and care homes.

It has been suggested that the cornerstone of the oral health service commissioning process is the understanding of the oral health needs of the population and the strategic development of services. This is dependent on having robust oral health needs data. Needs assessment is far from straight forward for the population with a learning disability and there is evidence to show that, at least amongst children, there are recruitment difficulties amongst those people from the most advantaged backgrounds and amongst the older cohorts. As a result, the oral health differences between children with a learning disability and the wider child population may be masked (Owens *et al.*, 2011). It is likely that it is equally challenging to access accurate oral health information for adults with a learning disability, particularly those people with profound and multiple disabilities where gaining

consent can be a complex process. In terms of planning services this raises important issues about how oral health needs assessment is delivered and it is suggested that further work is needed to establish the optimal way of securing participation in epidemiological studies (Owens *et al.*, 2011).

Stage 2 Mapping existing services – this refers to gaining a clear understanding of how services are currently provided, their quality, and any gaps that needs to be addressed. To achieve this, it requires drawing a number of strands of data together, including:

- Capacity, range and type of current services
- Effectiveness and safety
- Patient experience
- Access and choice (British Society for Disability and Oral Health, 2009a)

The last point should include an estimate of the number of people unlikely to be able to initiate a dental appointment or able to leave home to attend a dental practice and the current commissioned service capacity for people with a learning disability.

The BDA Case-Mix Tool

A potentially useful tool in mapping existing services is the 'case-mix model' (developed by the British Dental Association [BDA]) which allows objective assessment of the complexity of the provision of care for people with disability through a structured matrix (British Dental Association, 2010) it allows an evaluation of patient complexity, rather than the complexity of the dentistry being provided, using six independent criteria that, either solely or in combination, indicate a measurable level of patient complexity (see Table A). Each criterion is measured independently on a four point scale (where zero represents an average fit and well individual and A, B and C represent increasing levels of complexity) and covers both actual provision of clinical care and the additional pieces of work needed to facilitate care for many disabled patients. Developed as a tool to describe the complexity of the patient, its use can be expanded to commissioning and planning services; benchmarking between services; an individual caseload descriptor; and provision of a measure for appropriate remuneration reflecting levels of case

complexity (British Society of Disability and Oral Health, 2007). The case-mix model training pack is available from the BDA Website – **www.bda.org**.

A recent study evaluated the reliability of the case mix tool by reviewing the scores attributed to 10 hypothetical scenarios when assessing patient complexity (Burgess et al, 2011). The results indicated that further development of the criteria, validation and training, is needed. Regular use is also recommended in order to improve validity and reliability.

**Stage 3 Identifying what needs to change – ** a comparison of the needs assessment with existing service provision will highlight what needs to change. This will differ for every PCT, however common themes will include:

- Leveling access and improving choice for the segments of the population who cannot access or have difficulty accessing services

- Addressing areas of poor health

- Developing specialist services, and

- A stronger focus on commissioning preventive services (British Society for Disability and Oral Health, 2009a)

Dental services for people with a learning disability will need to be considered in each of the above parameters. In order to identify required service need accurately, an assessment of complexity of treatment is essential so that the appropriate workforce can be commissioned in a co-ordinated way. For example how much of the need can be met by the primary care dental team (including hygienists), how much requires a dentist with a special interest and how much requires specialist or consultant input. The DOH publication, National guidelines for the appointment of dentists with a special interest (DwSI) in special care dentistry(Department of Health, 2009c) provides guidance to PCTs and other planning and commissioning bodies on the appointment of dentists with a special interest in Special Care Dentistry including the competency frame work for the scope of treatment that can be undertaken.

Specialist oral healthcare provision for older people with disability, dementia or complex medical conditions falls within the remit of

Special Care Dentistry. Quality assurance criteria for a specialist in Special Care Dentistry are set out in *'The Commissioning Tool for Special Care Dentistry' (British Society for Disability and Oral Health, 2009b).* They are set out alongside those of a generalist dental practitioner and the dentist with a specialist interest in Special Care Dentistry in order to facilitate PCT's ability to identify what level of care is required to meet the identified need in their area.

5.5 Developing the Vision

Commissioners should develop a clear picture for future dental services that is informed by their five year strategic plan (British Society for Disability and Oral Health, 2009a). It should include:

- A clear **'patient offer'**, explaining what people can expect from NHS dental services and what their responsibilities are as patients

- A clear **'strategic commissioning plan'** to deliver the patient offer, taking account of current unmet need, predicted changes in the pattern of services needed (such as for older people with physical or learning disabilities), the range and type of services, the interface between primary and secondary care, and the capital and revenue elements associated with improving the infrastructure, including physical access, equipment (including domiciliary equipment) and IT

All this needs to be done with the backdrop of the NHS 2009 Constitution (Department of Health, 2009d) in mind, and in particular that:

- ***The NHS provides a comprehensive service, available to all*** – irrespective of gender, race, disability, age, sexual orientation, religion or belief. It has a duty to each and every individual that it serves and must respect their human rights. At the same time, it has a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population

- Patients have the right to expect their local NHS to assess the health requirements of the local community and to commission and put

in place the services to meet those needs as considered necessary

5.6 Making it Happen

'Primary Care and Community Services: Improving dental access, quality and oral health' (Department of Health, 2009e) sets out commissioning levers under nine broad headings, which if used intelligently can deliver rapid improvement and the reader is referred to that document for further information on each of them. It also provides a useful list of the relevant regulations from which the legislative frame work related to PCTs powers to manage contracts is drawn.

This view of WWC fits well with the four aims of the commissioning strategy set out in *'The Commissioning Tool for Special Care Dentistry' (British Society of Disability and Oral Health, 2007)* which are:

1. The patient centered service, which aims to provide and maintain the optimum oral health for the individual or group.

2. Integrated front line delivery which is organised around the needs of the vulnerable adult rather than professional boundaries.

3. Integrated processes which lead to effective joint working.

4. Joint planning and commissioning.

Use of these two guidance documents (British Society for Disability and Oral Health, 2007 and 2009a) in combination will lead to the provision of a robust strategy and operational plan to meet the oral health needs of people with a learning disability.

5.7 Commissioning More than Dental Treatment

The scientific background and recommendations for oral health promotion go further than the consideration of dental treatment and include the following domains which put commissioning of oral health care into a broader context.

1. Creating Supportive Environments

Commissioners can 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: providing oral health education, a healthy diet, oral hygiene facilities, appropriate dental services, and encouraging the inclusion of oral health in care plans.

Additionally, Strategic Health Authorities and Primary Care Trusts must work with water providers to adjust fluoride in the water to the optimal 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 and are more likely to have decayed teeth extracted. Thus, water fluoridation has a potentially greater benefit for people with learning disabilities than it has for those sectors of the population who are more able to access restorative dentistry, such as fillings and crowns.

2. Building Healthy Public Policies

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

Education for children and adolescents with learning disabilities takes place both in schools dedicated to their needs and in mainstream schools, with and without specialised units. As it is important that an inclusive approach is taken to capture the population of children and adolescents with a learning disability in education, all schools should be included in building healthy public policy through the joint Health Improvement Plan.

3. Strengthening Community Action

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

4. Developing Personal Skills

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

5. Re-orientating Health Services

As well as provision of dental treatment, Commissioners should promote oral health prevention for health gain, away from curative and clinical services. This is particularly important in meeting the needs of people with a learning disability who find the receipt of restorative care challenging and can only manage with difficulty. With time, the success of the use of preventive therapies (such as fluoride) will allow services to be purchased in a way that gradually shift resources, personnel, skills and facilities towards disease prevention in people with learning disabilities. An immediate shift is not feasible as the backlog of dental treatment need can not be ignored and must be simultaneously addressed. For the time being there needs to be co-ordination between delivery of appropriate treatment services and appropriate health prevention.

5.8 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 and ensure that:

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

- The attainment of objectives is regularly audited or evaluated, and the results used as a basis for continuous improvement of oral health programmes. A minimum of 10% of the resources available to a programme should be devoted to evaluation (Levine and Stillman-Lowe, 2000). All those involved in the programme should participate in its evaluation, including the target group, their carers, providers and commissioners

- Oral Health promotion is multidisciplinary. Those disciplines that 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; and those involved in the provision of care, such as parents, mangers of care homes and community homes and care assistants

- Oral health promotion messages for people with learning disabilities are based on the Scientific Basis for Dental Health Education (Levine and Stillman-Lowe, 2000), the COMA reports on dietary sugars, dietary and weaning reference values (C.O.M.A., 1989, C.O.M.A., 1992) and any local food and nutrition or infant feeding guidelines. Oral health promotion messages should fit into the overall context of good general health, including physical, mental and social well being

- Those people working to promote the oral health of people with learning disabilities are required to be appropriately trained. Support from the community learning disability team can be invaluable

The Department of Health (2010b) is revising the dental contract, which will focus on quality rather than quantity and remunerate dentists on the quality of care they provide and the health outcomes they achieve rather than on the amount of dental treatment they provide. If the aspirations become reality, this contract should be of benefit to people with learning disability.

5.9 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.

There is also a move towards developing health passports for people with a learning disability that people 'own' and carry with them from one health/social care provider to the next to foster more of a holistic approach to care.

Care home registration and inspection, currently managed by local authority social services transferred to a single National Care Standards Commission (and an equivalent within the National Assembly of Wales) under the Care Standards Act (2002). It has resulted in registration of social care workers, setting standards in social care work and regulation of care workers training and education. It has led to the importance of good oral care being recognised within the care standards set for care homes and carers.

Recommendations

- Primary Care Trusts, Health Boards or equivalent responsible bodies have a duty of care for their local population

- Ask local responsible bodies if they have carried out a needs assessment. If yes, what were the findings and what are they doing as a result of the findings? If no, when are they planning to do the assessment?

- Commissioners should encourage Health Improvement Programmes

- Joint Investment Plans should ensure collaboration between Health Authorities and Social Services/Social Work Departments

- Commissioners should encourage Joint Investment Plans that ensure oral health is integral to the development of services

- Promote oral health care by working with various agencies (Levine and Stillman-Lowe, 2000)

- 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 (Rose, 1995)

- Encourage Health Care Professionals to provide support and help meet health care needs (Department of Health, 2004)

- Enable Community Learning Disability Teams to help with access to dental care (Rose, 1995)

- Encourage Community Learning Disability Teams to include representatives from the dental profession

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Table A. BDA Case-Mix Tool Descriptors

Criterion	Type of factor considered
1. Ability to communicate	Need for interpreter or other means of communication; degree of learning disability or dementia
2. Ability to co-operate	Additional appointment time or acclimatisation visits required; need to use sedation or GA
3. Medical status Treatment	Modification required; degree of impact of medical and psychiatric condition on the provision of care
4. Oral risk factors	Ability to carry out oral hygiene; dietary conditions, e.g. PEG feeding, severe xerostomia
5. Access to oral care	Support of carer required to get to the surgery; use of wheelchair recliner or hoist; need for domiciliary care
6. Legal and ethical barriers	Degree of capacity to consent; need to consult with other professional or carers; need to hold best interest meetings or case conference

(Dougall and Fiske, 2008a)

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 (Disability Discrimination Act 2005) to the benefit of both the patient and the dental student. Secondments to local Salaried Primary Care Dental Services also enhance this process by, seeing and caring for patients in a community setting.

The General Dental Council's document 'The First Five Years' (General Dental Council, 2002) and the Interim First Five Years (General Dental Council, 2008) outline disciplines and subjects which must be an integral part of the dental undergraduate course and within this are those areas relevant to people with disabilities. A further document produced by BSDH. Developing an Undergraduate Curriculum in Special Care Dentistry (Nunn et al, 2004) sought to develop the undergraduate curriculum with special reference to Special Care Dentistry. Within this document there are specific areas described which could be related to care of those with learning disabilities. The emphasis is on disability awareness and integration of all patient groups into the practice of dental care.

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. Specific courses designed to enhance understanding of dental care for those with disabilities include the Diploma in Special Care Dentistry (Royal College of Surgeons of England and the Membership in Special Care Dentistry – Royal College of Surgeons of Edinburgh), all of which have components relating to learning disability.

In order to develop a highly skilled workforce, a formal framework underpinning training and qualifications is recommended (Brookes and Master, 2010).

Postgraduate training

Specialist training in Special Care Dentistry came into place in the UK in September 2008. The General Dental Council (GDC) holds the Specialist List of dentists registered on this list through recognition of their skills and experience or training in this field of dentistry. The public are able to access this list via the GDC website – www.gdc-uk.net/searchregister.

The first diet of the Tri-collegiate Diploma of Membership in Special Care Dentistry (M SPEC CARE DENT) will be held in June 2012. The examination aims to test the knowledge of Special Care Dentistry at a level expected of a specialist practitioner and tests the attainment

of competence in the planning and execution of Special Care Dentistry requisite for specialist practice.

6.2 Training for Dental Care Professionals (DCP)

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.

With the requirement now for all DCP's to be registered with the GDC, there is a greater emphasis on continuing professional development (General Dental Council, 2007).

6.3 Training for Dental Care Professionals

All health care personnel should receive additional training to support the concept of integrated oral health care (Sheiham, 1993). 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 should be established for professional carers that are based on scientific principles, which stress that poor standards of oral hygiene can be a health risk for some patients. These could be integrated within existing staff induction programmes, which can overcome some of the difficulties of releasing staff for training (Fiske et al., 2000a) 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 (World Health Organisation, 1998, Sheiham, 1993). Training can be provided through National Vocational Qualifications.

Recommendations

6.1 Training for dentists

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Undergraduate Teaching Component

- Ethics and jurisprudence (General Dental Council, 1999) 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 Salaried Primary Care Dental Services

- The care of people with learning disabilities should be an essential component of Dental foundation training for dentists. Experience in General Dental Practice, the Salaried Dental Services and Hospital

- Service posts should be arranged to consolidate their professional development

6.2 Training for Dental Care Professionals

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- A Diploma in Dental Care Professional Studies with Modules on Special Care Dentistry has been developed by the Postgraduate Medical and Dental Education (PGMDE) Section of Cardiff University

- Integrated study days should be developed with other health care professionals

- Courses need to be available nationwide

- Courses should be developed which will enable DCPs 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

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- 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 curriculum for general nursing degrees and diplomas

7

Consent to Treatment and Clinical Holding

7.1 Introduction to consent

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

The Consent Process

It is a general legal and ethical principle that valid informed consent must be obtained before starting treatment, physical investigation or providing personal care for a patient. This principle reflects the right of patients to determine what happens to their own bodies and is a fundamental part of good practice.

For consent to be valid, it must be given voluntarily by an appropriately informed person who has the capacity to consent to the intervention question. The patient must be able to make a free choice (i.e. free from pressure). Consent is a process, not a one-off event, and it is important that there is continuing discussion to reflect the evolving nature of treatment.

Children under the Age of 16

In the UK, individuals with parental responsibility for a child may consent to dental care, whether or not the child has learning disabilities. This includes the giving of consent to a general anaesthetic, which is usually the most risk-prone procedure in dentistry.

The important consideration here is that the person giving consent must fully understand the procedure to which they are consenting. Where there is no one with parental responsibility present, or the parent for whatever reason cannot consent, it is possible for a court to give that consent, when it is in the best interests of the child to have the treatment carried out.

A young person under 16 can consent to treatment provided he or she is competent to understand the nature, purpose and possible consequences of the treatment proposed.

Adults Aged 16 or Over

The present position in the UK is that no person can consent to the treatment of another adult aged 18 (16 in Scotland) or over, even if they are the parent of that adult.

For an adult to consent to treatment they must have capacity to consent to that treatment. Capacity to consent is addressed by the Mental Capacity Act 2005 and by the Adults with Incapacity (Scotland) Act 2000.

Capacity and Incapacity

The Mental Capacity Act 2005 identifies means of assessing the capacity to make a decision about a particular action. The act uses 5 principles:

1. A person must be assumed to have capacity unless it is established that they lack capacity.

2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

3. A person is not to be treated as unable to make a decision merely because they make an unwise decision.

4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

The law in Scotland generally presumes that adults are capable of making personal decisions for themselves and of managing their own affairs. For the purposes of the Adults with Incapacity (Scotland) Act 2000, "incapable" means incapable of:

- Acting on decisions; or
- Making decisions; or
- Communicating decisions; or
- Understanding decisions; or
- Retaining the memory of decisions

In relation to any particular matter due to mental disorder, or inability to communicate because of physical disability.

Principles to be followed:

- Benefit – any action or decision taken must benefit the person and only be taken when that benefit cannot reasonably be achieved without it

- Least restrictive option – any action or decision taken should be the minimum necessary to achieve the purpose. It should be the option that restricts the person's freedom as little as possible

- Account must be taken of the present and past wishes and feelings of the person, as far as this may be ascertained

- Consultation with relevant others with an interest in the person's welfare

- Encourage the person to use existing skills and develop new skills

The Mental Capacity Act and the Adults with Incapacity (Scotland) Act have codes of practice provided by the relevant authorities to clarify principles and practice in applying legislation (Department for Constitutional Affairs, 2007, Scottish Government, 2007).

Assessing Capacity

Processes will be defined locally and are dependent upon the applicable law. In essence, an individual's capacity to consent to a particular procedure is specific to the particular procedure and at the time of the procedure.

The assessment of a patient's capacity to make a decision about medical treatment is a matter for clinical judgement guided by professional practice and subject to legal requirements.

To demonstrate capacity individuals should be able to:

- Understand (with the use of communication aids, if appropriate) in simple language what the medical treatment is, its purpose and nature and why it is being proposed;

- Understand its principle benefits, risks and alternatives;

- Understand in broad terms what will be the consequences of not receiving the proposed treatment;

- Retain the information for long enough to use it and weigh it in the balance in order to arrive at a decision;

- Communicate the decision (by any means)

In Scotland a Health Practitioner may assess the individual capacity to consent and must formally record the assessment. The area to which the assessment applies must be within the skills and knowledge of the individual practitioner.

Approved codes of practice have been developed to address the different legal arrangements. (British Medical Association, 2007, British Medical Association, 2009, General Dental Council, 2005a)

For all patients, information should be presented in a manner appropriate to their understanding. This includes explanations and consent for screening as well as dental treatment.

Best Interests

All decisions about care where an individual lacks capacity must be taken in their 'best interests'. This common law principle is now legislated for in the mental capacity and adults with incapacity legislation. To demonstrate consideration of best interests a clear record must be made of:

- How the decision about the person's best interests was reached

- What the reasons for reaching the decision were

- Who was consulted to help work out best interests, and

- What particular factors where taken into account

Independent Mental Capacity Advocate

Where serious medical treatment is proposed and an individual is understood to lack capacity for a decision, if there are no relevant others to consult on an individual's behalf, the Mental Capacity Act allows for an IMCA to be involved in the consent process for the patient.

Record Keeping

Local arrangements must be in place for recording the consent process including the information given and the processes used to assess capacity and obtain consent.

7.2 Clinical Holding

Within special care dental practice, it may be necessary in some circumstances to use physical holding techniques in order to provide safe and appropriate oral health care. Specialist Clinical Holding Skills for Dental Services (Clinical Holding) are defined as follows, to reflect the specific context related to dental examination, treatment or oral health care:

'the use of physical holds (clinical holding), to assist or support a patient to receive clinical dental care or treatment in situations where their behaviour may limit the ability of the dental team to effectively deliver treatment, or where

the patient's behaviour may present a safety risk to themselves, members of the dental team or other accompanying persons'

The BSDH Guidelines for 'Clinical Holding' Skills for Dental Services for people unable to comply with routine oral health care (British Society for Disability and Oral Health, 2008) are founded upon and are congruent with current standards of professional practice in dentistry:

- The impact of oral ill-health on the patient's quality of life can be profound. Good oral health has positive benefits for health, dignity, self esteem, social integration and general nutrition

- Healthcare professionals providing dental care and treatment share common values and a commitment to working within the law, adherence of accepted clinical and professional standards and above all, operating within the best interests of the service user

- Everyone has a right to equal access and equal standards of health and care

- Everyone has a right to autonomy in relation to decisions about their healthcare, or have the right to have as much help as possible to make such decisions

- Any treatment should only be carried out with due consideration to the patient's best interests and represent the least restrictive and detrimental option

- Everyone has a right to be safe

- Practitioners should work in a manner that promotes the long term well-being and interests of patients in order to address health inequalities of some patient groups and to deliver improved health outcomes

The principles outlined must be communicated to all members of the multi-professional team managing and delivering the patient's treatment, as well as patient's relatives and advocates, in order to support a positive and proactive approach to oral health care rather than merely authorising ways of managing difficult patient behaviour. Clinical holding should be used as infrequently as possible and used in the best interest of the patient in order to deliver appropriate treatment outcomes whilst at the same time ensuring that the patient's sense of dignity is fully maintained.

Context and Rationale

The context for the guidance relates to those situations where a clinical team has determined that a patient's assessment or course of treatment cannot be carried out effectively and/or safely as a result of the behaviour presented by the patient. Whilst it is acknowledged that in real-life situations there are numerous factors that may influence the patient's behaviour and the level of risk such behaviour may present during oral examination or treatment, it is the professional responsibility of the Dentist, Dental staff, or other staff members involved in undertaking the treatment to consider their own general conduct and give due diligence to any decision to initiate, continue or cease using clinical holding. In general, such behaviour or risk is uncommon but may typically arise in patients who lack capacity or may be unable to comply due to their personal characteristics. For example, clinical holding may be appropriate when treating:

• Some patients with learning disabilities and/or autistic spectrum disorder;

• Some patients with involuntary movements or an inability to control their movement;

• Some severely anxious patients;

• Some patients who lack capacity and the ability to understand and co-operate with a specific clinical intervention of treatment

The issue of concern relating to patients who are unable to comply with routine treatment is more often about the safe delivery, rather than the appropriateness of the specific oral health care required. Clearly, practitioners have a duty of care to ensure that identified care and treatment is provided in an effective and safe way. In this respect, the decision to use clinical holding must be considered alongside a range of other issues and consequently, in order to meet the current standards of professional practice, the use of non-physical and non-intrusive strategies must remain the preferred approach to support treatment. Therefore, when considering the use of clinical holding, a number of factors must be addressed through the patient's treatment plan including:

There will be known triggers for behaviour change in some patients which will help practitioners to make decisions which specifically relate to each patient at the time the treatment is carried out;

• The timing of appointments., medication and other aspects of daily routine may be crucial in delivering effective treatment outcomes for some patients;

• The use of augmentative techniques (such as relaxation techniques, music therapy, embedded commands etc.) may be beneficial with some patients in gaining improved co-operation;

• Acclimatisation, behaviour modification and consistency may improve compliance for some patients and therefore remove the need for clinical holding;

• Compliance from the patient may not be consistent or predictable and may vary with different procedures on different days or with different carers or professionals present. A particular approach to treatment today may not be an appropriate approach with regard to the next course of treatment the patient requires

• The use of appropriate communication strategies to maximise opportunities for care

Health professionals should have concern for the legality of the use of clinical holding and also, the professional and ethical issues of such practice.

Anyone who has a learning disability has the same rights as those who do not, and should therefore be a recipient of the same benefits afforded to others in society. As such, clinical holding should not compromise these rights and should seek to maintain a person's dignity.

The use of clinical holding skills must be clearly underpinned with appropriate legal, professional and ethical knowledge and understanding.

• It must also be supported by appropriate and specific training from an accredited organisation

• The staff should be following nationally and locally accepted protocols and policies

• The potential hazards associated with the use of clinical holding must be systematically evaluated and never involve unreasonable risk.

The dentist must consider, in the interests of patient safety, whether the treatment would be more effectively and safely completed under sedation, or general anaesthesia. See sections 3.6 and 3.7.

The issue for this group of people is often more about the delivery of oral and dental care rather than the care itself. Clinicians who have a duty of care also have a duty to provide that care in a manner that is beneficial to the patient. Both the method of delivery and the treatment must be considered during the consenting process.

- There are a number of factors that must be considered and included within any oral care plan. These should be included as an integral part of multi professional discussions leading to decisions made about oral care

On occasions, where other behaviour management strategies have failed, or are obviously not appropriate, some form of intervention will be required. Oral, inhalation, intravenous sedation or general anaesthesia used as adjuncts to facilitate dental care, must be viewed as pharmacological intervention. It is important to realise that there are times when reasonable physical intervention (clinical holding) is preferable to more extreme alternatives and might be acceptable for single, short interventions. However, such an approach should only be countenanced when all other approaches have been considered. There will be occasions on which resorting to general anaesthesia (GA) is appropriate but it must be recognised that rendering a patient unconscious constitutes the ultimate in physical intervention (a patient lacking the capacity to consent also lacks the capacity to withdraw treatment). A competent patient can withdraw consent at any time and this must be considered; rendering a patient unconscious will entirely remove their ability to withdraw consent and even the use of sedation may hamper their ability to withdraw consent.

7.3 Guiding principles on the use of clinical holding

The Department of Health in England defines:

Restraint as "The positive application of force with the intention of overpowering the person', which, by definition, is without that person's consent.

Holding still as immobilisation, which may be used to help a person cope with a painful procedure effectively and is carried out with the person's consent. It differs from restraint in the intention and degree of force required.

Containing is physical restraint or a barrier aimed at preventing the person from harming themselves or others.

Whilst the term restraint has been in common usage, there is a move away from it an instead to substitute the term; physical intervention, to avoid the negative connotations that the word "restraint" has in the Learning Disability field.

Clinical Holding is the use of physical holds to limit or restrict an individual's ability to move during the provision of 'safe care'. Holding involves the use of graded physical responses along a continuum of restriction that is appropriate and proportionate to the level of risk presented.

"Safe Care" relates to situations where a person is held in order to enable someone to provide the individual with an agreed level of support, help, care or treatment agreed within the individual's support plan.

The Department of Health Guidance for Restrictive Interventions (Department of Health and Department for Education and Skills, 2002) gives advice on the provision of safe services for people with Learning Disabilities and Autistic Spectrum Disorder. The Guidance distinguishes between "planned interventions" and "unplanned or emergency interventions", both of which may be appropriate in the provision of oral care. The Guidance is, however, aimed less at those providing therapeutic interventions but more towards carers in schools and day centres.

The responsibility for therapeutic/procedural clinical holding lies with the "treating" dentist. This is the case irrespective of who undertakes the intervention – a member of the dental team trained in clinical holding, or a parent or accompanying person with responsibility for the Client. Parents or accompanying responsible persons have a vital role to play not only in supporting any clinical holding but also in expressing their concerns if they are uncomfortable with the procedure. However, they must be made fully aware of the consequences of not only continuing with, but also prematurely curtailing, the procedure and the implications for not completing dental care.

Recommendations

1. The practice of clinical holding must be underpinned by an ethos of caring and respect for the individual's rights.

2. Practice should be based around clear and accepted policy and national guidelines.

3. There should be sufficient numbers of staff within the dental team who are appropriately trained and updated in the use of safe and accepted techniques.

4. A risk/benefit assessment must be carried out before the use of clinical holding.

5. Accurate record taking is vital to the process.

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Clinical Holding Techniques

Photographs courtesy of Dr Selina Master

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 a primary source of knowledge and expertise on all aspects of learning disability. They also have a vital role at national and local level in championing rights for equal access to equally effective healthcare, not least dental care.

The sector consists of large national organisations and small local associations, most of which are concerned with specific conditions or syndromes. The most well known are Mencap, the Down's Syndrome Association and the National Autistic Society. The range of organisations involved includes:

- Self-advocacy groups, in which people with learning disabilities come together to find strength in unity, explore common problems and share solutions

- Citizen advocacy groups working in partnership with people with learning disabilities to inform them of their rights, help them assert those rights

- Parent and carer groups in which members learn from each other's experiences, and work together for greater success and a diminished sense of isolation

- 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 services, usually under contract from the statutory agencies, and sometimes with added value from voluntary input

Many of the larger organisations produce specific information on oral care. For example, Mencap has an 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. The Profound and Multiple Impairment Service - PAMIS in Scotland has also developed training programmes on dental care and oral health specifically for people with profound and multiple learning disabilities and has written a leaflet on Oral Health Care (PAMIS, 2011). PAMIS has also developed a multi-sensory story on visiting the dentist.

A list of some of the main voluntary bodies in the learning disability field together with contact details are shown in section 10. Also a list of oral care resources currently available on the internet can be found on the "Information for the Public" section www.bsdh.or.uk.

With specific regard to the guidelines in this document, the voluntary sector can provide invaluable practical assistance in ensuring the dissemination and implementation. Oral health and dental care may not be mainstream to their activities but does make a significant contribution to quality of life in terms of peoples' appearance, social inclusion, eating, speech and freedom from pain and discomfort. Promoting wider awareness of this with their members and of the means of achieving better oral health set out in this document, would undoubtably improve the oral health of people with learning disabilities. In addition, communication and partnership working with those responsible for dental services is vital to improving their availability and quality.

Examples of this are:

- Lobbying PCT's/Local Health Boards to ensure the needs of people with learning disability are heard and taken into account in commissioning of services and decisions about local service prioritisation

- Contributing to disability awareness and other training of dental staff through undergraduate and postgraduate courses and in-service settings

- Drawing attention to reasonable adjustments that are needed in order to improve services and participating in surveys on access to services and user satisfaction

- Developing local knowledge of dental service providers to provide signposting for people to dentists working in either the General Dental Services or Salaried Dental Services that can offer care appropriate to individual needs

There is a major challenge to improve the poor oral health of people with learning disability and secure their access to NHS dental services which are under threat in many parts of the country. While the voluntary sector has a successful track record of influencing policy at national level, the shift of responsibility for policy implementation and prioritization to local level requires a corresponding focus of activity at local level. Dental providers and voluntary organizations need to work together locally if they are to ensure that oral health and access to dental services are not allowed to deteriorate further.

Recommendations

Voluntary Organisations should:

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- Use their networking and organisational skills to disseminate these guidelines and promote awareness of the significant contribution of oral health to the quality of life of people with learning disabilities

- Lobby local PCT's/Health Boards to ensure equitable access to dental care services under the terms of the *Disability Discrimination Act 2005*

- Promote methods of achieving better oral health in residential and support facilities

- Collaborate with dental service providers to help them improve their quality of care and information provided

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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 can aid the delivery of treatment e.g. Hypnosis, acting alone or as an adjunct to sedation, providing relaxation techniques

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 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

Research in Special Care Dentistry

Special Care Dentistry (SCD) has grown out of recognition that some patients are different and that routine dental care does not answer the needs and demands of an increasing number of people in society today.

The evidence base to inform day to day practice in much of SCD has evolved slowly, with its origins in mainstream dentistry, subsequently modified by protocols, guidelines and Professional Statements from specialist societies. To date, research in SCD has often been confined to the oral health sector without consideration of inter-professional opportunities.

Much of the published research relating to this field, centres on provision of care to sub groups along with the inclusion of case reports on particular treatment modalities or case/ syndrome types. There is an emerging interest area in categorising potential SCD patients and their needs, although this is often driven by political or economic imperatives.

Under-researched areas in SCD include:

- The World Health Organisation's International Classification of Function, Disability and Health, should include within its framework considerations of oral health as an important development. An international group is being set up to progress this work. As with other areas of research, not only in SCD, multi-centre working is fundamental to gathering sufficient data to derive meaningful results. There is the potential to compare and align data collection tools, for example, the British Dental Association's Case Mix Tool and locally or internationally derived instruments to generate oral health data sets

- Users' perspectives are central to decision-making in UK health services, and participation in all phases of service delivery is now expected. Qualitative data in this area is lacking, as is often the training in appropriate research methodology amongst dental scientists who are more familiar with the collection and manipulation of quantitative data

- Allied to this area is that of barriers; whilst recognized as an impediment to successful entry into healthcare there is enormous scope for a more holistic approach to these and, alongside interdisciplinary working to include users, developing approaches that overcome barriers

- Maintenance of health, as opposed to managing disease, is a neglected area, in part because it is difficult to study. However, with health strategy driving value for money initiatives and the need to meet performance indicators, primary care in particular has a role to play in researching ways to achieve and maintain health as distinct from protocol-driven preventive and treatment strategies. Alignment with key national and international goals in this field opens up the potential for funding of research

- Cross-sectoral working in grey areas in SCD, such as consent and physical interventions opens up opportunities for research initiatives as well as clinical audit

- Much of the research that is undertaken in the UK in SCD is fragmented, stemming from the need to produce dissertations as part of academic courses alongside those working in primary/secondary care with a genuine interest in a discrete area of their work. A national body that can oversee and drive research initiatives could have its home within BSDH and ultimately, a section within research organizations such as IADR. Such a structure would enable those new to research to be mentored and opens up the possibility of collaborative and multi-centre working that is the lifeblood of groups seeking ever more scarce research funding

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Resources

Information on Organisations, Books, Teaching Programmes and Videos

Organisations

Association for Residential Care
ARC House, Marsden Street, Chesterfield,
Derbyshire S40 1JY
Tel: 01246 555043
e-mail: contactus@arcuk.org.uk

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

British Dental Health Foundation
Smile House, 2 East Union Street,
Rugby, CBV22 6AJ.
Tel: 0870 770 4000
e-mail: mail@dentalhealth.org
www.dentalhealth.org

British Institute of Learning Disabilities
Campion House, Green Street, Kidderminster,
Worcester, DY10 1JL.
Tel: 01562 723010 Fax: 01562 723029 e-mail:
enquiries@bild.org.uk Website: www.bild.org.uk

**British Society for Disability and Oral
Health**, www.bsdh.org.uk

Capability Scotland
Head Office, Westerlea, 11 Ellersley Road,
Edinburgh, EH12 6HY.
Tel: 0131 337 9876 Fax: 0131 346 7864
e-mail: ascs@capability-scotland.org.uk

Down's Syndrome Association
Langdon Down Centre, 2a Langdon Park,
Teddington, TW11 9PS
Tel: 0845 230 0372 Fax: 0845 230 0373
e-mail: info@downs-symdrome.org.uk
www.downs-syndrome.org.uk

Down's Syndrome Association of Scotland
158-160 Balgreen Road Edinburgh EH11 3AY
Tel 0131 313 4225 Fax: 0131 313 4285
e-mail: info@scotland.org.uk

ENABLE
2nd Floor, 146 Argyle Street, Glasgow, G2 8BL
Tel: 0141 226 4541 Fax: 0141 204 4398
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: ces@gdc-uk.org
www.gdc-uk.org

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

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
e-mail: office@ldascotland.org
www.ldascotland.org

**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
Central Chambers, 1st Floor, 109 Hope Street,
Glasgow, G2 6LL
Tel: 0141 221 8090 Fax: 0141 221 8118
e-mail: scotalnd@nas.org.uk

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 331 0987

PAMIS (Profound and Multiple Impairment Service)
Dundee University, 15/16 Springfield,
Dundee, DD1 4JE
Tel: 01382 385 154 Fax: 01382 227464
e-mail: pamis@dundee.ac.uk
www.pamis.org.uk

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
www.rescare.org.uk

SCOPE CP Helpline
PO Box 833, Milton Keynes, MK12 5NY
Tel: 0808 800 3333
e-mail: cphelpline@scope.org.uk
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 Fax: 020 7272 6012
e-mail: enquiries@sense.org.uk
www.sense.org.uk

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 Fax: 020 7833 9666
e-mail: nas@nas.org.uk
www.autism.org.uk

Welsh Centre for Learning Disabilities
Meridian Court, North Road, Cardiff CF4 3BL
On-line customer support –
www3.interscience.wiley.com/aboutus/
contactus

Additional New Resources

Guidelines

British Society for Disability and Oral Health

'Guidelines for the Delivery of a Domiciliary Oral
Healthcare Service' revised 2009

'The Provision of Oral Care under General
Anaesthesia in Special Care Dentistry' – A
Professional Consensus Statement, 2009

'Commissioning Tool for Special Care Dentistry'
A document produced by the British Society
of Disability and Oral Health and funded by the
Department of Health 2006

'Developing an Undergraduate Curriculum
in Special Care Dentistry' – Prepared by a
Working Group of the Teachers Group of BSDH

'Principles on Intervention for People Unable
to Comply with Routine Dental Care' – Clinical
Holding Guidelines Updated 2009

'Guidelines for Oral Health Care for Long-stay
Patients and Residents'

'Guidelines for the Development of Local
Standards of Oral Health Care for Dependent,
Dysphagic, Critically and Terminally Ill Patients'

'Oral Health Care for People with Mental Health
Problems: Guidelines and recommendations'

'Guidelines for Oral Health Care for People with
a Physical Disability'

'Guidelines for Oral Care of People with
Disabilities'

Produced by the Clinical Effectiveness Committee of the Faculty of Dental Surgery of the Royal College of Surgeons of England in association with BSDH

'Multi-disciplinary Guidelines for the Oral Management of Patients following Oncology Treatment'

British Society of Gerodontology:

'Meeting the challenges of Oral Health for Older People: A Strategic Review' – Commissioned and funded by the Department of Health and published as a supplement to Gerodontology December 2005

'Guidelines for the Development of Local Standards of Oral Health Care for People with Dementia' funded by the Department of Health and published as a supplement to Gerodontology December 2006

'Guidelines for the Oral Healthcare of Stroke Survivors' Guidance on the delivery of care to people affected by stroke – published by the British Society of Gerodontology in June 2010

SIGN Guideline 83: 'Prevention and Management of Dental Decay in the Pre-School Child' – www.sign.ac.uk/guidelines/published/numlist.html

Documents

Fissure Sealant Document: 'British Society of Paediatric Dentistry: a policy document on fissure sealants in paediatric dentistry'. International Journal of Paediatric Dentistry 2000; 10: 174-177. www.bspd.co.uk.

"Death by Indifference"

"Healthcare for All" – document on the "independent enquiry into access to healthcare for people with learning disabilities". Available from Mencap www.enquiries@aldridgepress.co.uk.

Delivering Better Oral Health: An evidence based toolkit for prevention London Department of Health.

Valuing People's Oral Health: a good practice guide for improving the oral health of disabled children and adults London, Department of Health

Books

'A Clinical Guide to Special Care Dentistry' The authoritative reference for dental practitioners and students – written by J. Fiske MBE , A. Dougall and D. Lewis. Published in 2009 by The British Dental Association, 64 Wimpole Street, London, W1G 8YS.

Topics in Autism – 'A Picture's Worth' PECS and Other Visual Communication Strategies in Autism – written by Andy Bondy, Ph.D., & Lori Frost, M.S., CCC/SLP. Published in the US of America by Woodbine House, Inc., 6510 Bells Mill Road, Bethesda, MD 20817 – www.woodbinehouse.com

'Health Care and the Autism Spectrum' A guide for Health Professionals, Parents & Carers – written by Alison Morton-Cooper. Published by Jessica Kingsley Publishers, 116 Pentonville Road, London, N1 9JB – www.jkp.com

'Asperger Syndrome and Sensory Issues' Practical Solutions for Making Sense of the World – written by Brenda Smith Myles, Katherine Tapscott Cook, Nancy E. Miller, Louann Rinner and Lisa A. Robins and Illustrated by Penny Chiles. Foreword by Winnie Dunn. Published by Autism Asperger Publishing Co, P.O. Box 23173, Shawnee Mission, Kansas 66283-0173.

'Sensory Perceptual Issues in Autism and Asperger Syndrome' Different Sensory Experiences, Different Perceptual Worlds – written by Olga Bogdashina – forewords by Wendy Lawson and Theo Peeters. Published by Jessica Kingsley Publishers Ltd, 116 Pentonville Road, London, N1 9LB

'Joey Goes to the Dentist' – written by Candace Vittorini and Sara Boyer-Quick. Published by Jessica Kingsley Publishers Ltd, 116 Pentonville Road, London N1 9LB

'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 Fax: 01772 722890 E-mail: admin@fairfiledpublications.co.uk

'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: 0207 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: 028253 635221

'Hospital Communication Book': www.valuingpeople.gov.uk/dynamic/ valuingpeople145.jsp

'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

'Shaw-Champion Teaching Makaton to Chloe 1997'. Down's Syndrome Association, 155 Mitcham Road, London SW17 9PG Tel: 020 8682 4001 Fax: 020 8682 4012 e-mail: info@downs-syndrome.org.uk www.downs-syndrome.org.uk/

'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

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

'Oral health care for people with profound and multiple learning disabilities' PAMIS, 15/16 Springfield, University of lDundee, Dundee DD1 4JE, Tel 01382 385 154 e:pamis@dundee.ac.uk

'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 www.scope.org.uk

Teaching Programmes

Mouth care 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, Nuneaton, Warwickshire CV12 9PD Tel: 02476640115

Videos/DVD's

Special Care Dentistry DVD – An Interactive Learning Programme for the Dental Team by Dr J Fiske MBE and Dr Roger Davies.

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

Healthy living and people with learning disabilities: a healthy life and a healthy smile. A DVD with booklet Produced by Event and Media Solutions, Social Work Service (Fife Council) and Fife Community Dental Services, Tel:0845 555555 ext 444813 or email event.mediasolutions@fife.gov.uk

Teeth for Life
Who Cares?
Pretty Clever Pictures
Shepperton Studios, Shepperton Road, Shepperton, Middlesex TW17 OQD
Tel: 01932 592322

Other Useful websites/ resources

www.makaton.org

www.signature.org.uk - info on BSL

www.signalong.org.uk

Talking Mats: A resource to enhance communication

Talking Mats and Learning Disability

http://sensorytoolkit-offtothedentist.co.uk/

Toolkit for children and adults with Autism Spectrum Disorder

Leaflets

NAS Leaflets – Dental Care and Autism Leaflet – available to download from The National Autistic Society website: www.nas.org.uk

VDP Leaflet –
www.heatherwoodandwexham.nhs.uk/ patient_info/information_leaflets/dental.pdf

Helpful Information and tips for Dry Mouth
www.patient.co.uk/health/Dry-Mouth.htm

'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)
PO Box 26642, London, N14 4ZF.
Tel: 020 8394 3010 E-mail: info@nspku.org

www.surreyhealthaction.org.uk/health-services-in-surrey-made-easy.going-to-the-dentists-surgery

Easy read leaflets on:

- Special Care Dental Service in Surrey
- Looking after your teeth – including Dentures
- Appointment letter
- Appointment reminder

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 preregistration 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), now the Salaried Dental Services (SDS): 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 specialties 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.

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Down's Syndrome Association

ENABLE

Mencap

Section for Independence Through Education (SITE), The City Lit, Stukely Street, Drury Lane, London WC2B 5LJ

Comments from Service Users

"I like having my teeth counted and when I clean my teeth will 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."

Explanatory Notes, Discussion and References

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.

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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"

"The dentist talks to me"

"He doesn't make me feel afraid"

"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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