

Valuing People's Oral Health

A good practice guide for improving the oral health
of disabled children and adults



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Valuing People's Oral Health

A good practice guide for improving the oral health of disabled children and adults

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Foreword by the Chief Dental Officer of England



This document is the third in a series of supplementary guidance documents following on from the publication of

Choosing Better Oral Health: An oral health plan for England. We pointed out in this plan that, despite the very encouraging improvement in oral health in England, there remain very marked inequalities in oral health. Vulnerable groups in particular are certainly more at risk from poor oral health.

We know that children and adults with disabilities and people with mental illness tend to have fewer teeth, more untreated decay and more periodontal disease than society at large. However, disabled people have the same entitlement to good oral health as the rest of the population.

We therefore commissioned an expert group of stakeholders to look specifically at the oral health needs of disabled people and produce guidance on how oral health could be improved for these vulnerable groups. This document does not cover treatment provision but is designed to support primary care trusts (PCTs) and their advisers in their needs assessment and commissioning of preventive oral health services.

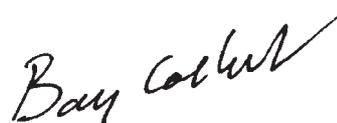
Although not focusing just on oral health improvement in children and adults with learning disabilities, but more on disabled people in general, *Valuing People's Oral Health* carries forward into oral health many

of the key principles in *Valuing People*, the Government's White Paper on learning disability, hence the title that we have given to this document.

The working group took particular note of the resources recently made available to PCTs and dental practices through the evidence-based toolkit *Delivering Better Oral Health*. The preventive guidance in *Valuing People's Oral Health* concurs fully with that published in the toolkit.

The NHS has a responsibility to ensure the equality of provision of care to all groups in society and I am sure that, if implemented correctly, the guidance within this document will be of great help to both PCTs and their dental contractors in improving the oral health of their local disabled residents.

I should particularly like to thank Colette Bridgman who chaired the working group, Clare Jones who worked very hard to collate the content and all the members of the working group, specialist societies and associations whose input has been so valuable in producing such an excellent resource.

A handwritten signature in black ink that reads "Barry Cockcroft". The signature is written in a cursive, slightly slanted style.

Barry Cockcroft
Chief Dental Officer

Executive summary

- 1 A time of change and reform is also a time of opportunity. The publication of this supplement to *Choosing Better Oral Health* (Department of Health, 2005b) is timely. It can inform and influence the emerging and strengthened commissioning role of primary care trusts (PCTs). It is intended to influence the provision of key actions, oral health programmes and services required to improve and secure oral health for disabled children and adults.
- 2 *Choosing Health: Making healthy choices easier* (Department of Health, 2004b) acknowledged that some people have difficulty using the health information available to them because they suffer from learning or physical disabilities. It advised, as below, that new primary care arrangements will be important in helping those with chronic or multiple medical conditions, or disabilities, to make the most of their health: 'Most... are able to maintain reasonable general health with support from others. With assistance in developing their skills they can take greater control of their own health, and their lives.'
- 3 Disabled children and adults have the same entitlement to good oral health as the rest of the population. This inclusive description covers large numbers of client groups and within each group there will be a 'pyramid spectrum' of need and dependency, with limited numbers of people at the highest level of need and dependency. Oral health is an important factor in overall health and well-being. Good oral health can promote good communication, good nutrition, positive self-esteem and can lead to a reduction or elimination of discomfort from the teeth or mouth. Poor oral health can reduce a person's ability to consume nutritious food, affect self-image and confidence, and cause significant pain, which a person with an impairment or disability may not be able to communicate. The benefits of good oral health can be under-estimated; good oral health empowers disabled children and adults, giving them the confidence to enable them to reach their full potential in participating in all aspects of society.
- 4 These groups of people also have an equal right to responsive oral health services. For some, this requires that additional action and support is in place to overcome barriers. At the same time as taking action to improve oral health, it is important to value and develop competence in provision of oral healthcare to these groups through research, consistent advice, professional training and provision of specialist care (for example paediatric dentistry and special care dentistry services*) to meet identified needs. Treatment of preventable dental diseases is costly to all involved, not only for

* In 2004, the Standing Dental Advisory Committee completed its review of the dental specialties and made the recommendation that the General Dental Council should **consider** the establishment of a new specialty, that of special care dentistry.

the PCTs and specialist services, but also for the patients and the parents and carers of disabled children and adults, who may have to take time off from employment and fund transport to accompany patients for assessment and treatment.

- 5 Oral health needs to become integrated into holistic health policy at all levels and should be included in every individual care plan. Oral health issues are often overlooked; doctors and dieticians, for example, do not always think about the oral health implications of the medication and diets they prescribe and advise, nor do they always know the control measures that could be taken to minimise harm when such medication or diets are essential. Effective integration of oral health into the mainstream health agenda is required to ensure that oral health issues are not omitted or dealt with separately and seen as 'the dentist's problem'. **Oral health is everyone's business.**

Key recommendations

- 6 The key recommendations of this supplement are as follows:
 - Assess need through local surveys**
 - > Carry out routine oral health needs assessments of disabled children and adults in line with population surveys (paragraphs 13–15).
 - > Disabled children and adults, and those involved in their care, need to receive the

necessary information, advice, support and resources so that they have the best opportunity to achieve and maintain optimal oral health (paragraph 27).

Design and implement effective preventive actions and programmes

- > These programmes should be informed by the evidence (paragraphs 29–31).
- > Preventive actions and programmes should be consistent with the recommendations of *Delivering Better Oral Health: An evidence-based toolkit for prevention* (Department of Health, 2007) (paragraph 31).

Consistency of messages across all health and social care boundaries

- > It is best practice for all health and social care professionals to provide 'at-risk' groups of patients, and their carers, with the same positive oral health education messages (paragraphs 24 and 28).
- > Use national support groups to promote consistent oral health messages and ensure that up-to-date information is available for local branches (paragraph 24).

Build competence through training and sharing of knowledge

- > It is good practice for personnel involved in the care of disabled children and adults to receive appropriate training and for them to be provided with information about services available and preventive actions that work (paragraph 28).

Include oral health in every care plan

- > It is best practice for children and adults with an impairment or disability to have a comprehensive oral health care plan embedded within their overall health plan (paragraphs 28 and 42).
- > A local champion for oral health can be responsible for putting systems and processes into place so that oral health care plans are followed and that disabled children and adults have access to preventive and treatment services when required (paragraph 27).

Responsive, needs-led treatment services

- > Commission accessible, prevention-focused primary care services (paragraphs 38, 40–42 and 43).
- > Commission timely, responsive, needs-led specialist care (paragraphs 39 and 43).

Information for people whose first language is not English

- > Provide multilingual information or translation as appropriate (paragraphs 28 and 43).

Equality Impact Assessment

- 1 *Valuing People's Oral Health* complements the Government's oral health plan for England, *Choosing Better Oral Health* and, as such, is specifically concerned with **preventing** dental disease in those vulnerable people who consider themselves to be disabled, as well as specific groups within this population, for example those who are considered to have learning disabilities. Its aim is to promote equality of opportunity by ensuring that disabled people and their carers receive appropriate advice on how to prevent oral diseases. It does not cover the availability or appropriateness of treatment modalities for disabled people as this is available from other sources (British Society for Disability and Oral Health, 2000 and 2001).
- 2 An equality screening was undertaken of the *Valuing People's Oral Health* policy programme and, following this, a full Equality Impact Assessment was carried out. In general, it was not felt that the guidance within the document would lead to discrimination against any societal groups nor would lead to public concern in any way. The following specific issues were reviewed.

Age

- 3 The physiology of oral disease means that oral health needs are different between children and adults with or without disabilities; therefore, the approach to oral health must vary according to the patient's age. *Valuing People's Oral Health* clearly distinguishes

the differing preventive approaches across age groups to ensure equitable outcomes.

Disability

- 4 There is published evidence that disabled people are at risk from higher levels of oral health need. This best practice guidance specifically addresses oral health needs in disabled people and makes evidence-based recommendations about how oral health may be improved.

Race

- 5 We recognise that a disproportionately high number of people from black and minority ethnic (BME) groups, including disabled people within these groups, live in areas of high social need, which is directly correlated with poor oral health. For this reason, the Chief Dental Officer is establishing a multicultural working group with the aim of producing, in spring 2008, a best practice guidance document for improving oral health in BME groups. Key issues that impact on oral health in these areas – such as diet, smoking and the use of smokeless tobacco products – will be covered in this document. *Valuing People's Oral Health* recognises that, in providing preventive advice for disabled people, the fact that English may not be their first language needs to be taken into consideration, including the availability of interpreters, and the importance of advice booklets and information being available in a number of relevant languages.

Potential for benefit

- 6 We believe that this guidance document has a high potential for benefit and will be welcomed by disabled people and their carers. The preventive advice is based on evidence-based information within the recently published preventive toolkit, *Delivering Better Oral Health*. If PCTs accept the recommendations in this report and commission preventive care, in the short term we would expect to find a much greater emphasis on health improvement in these groups, and in the longer term we would expect to see improved oral health measured against baseline data.

Evaluation

- 7 PCTs are bound by statute, when carrying out their functions, to have due regard for the need to eliminate unlawful discrimination and to promote equality in terms of disability, race and gender, and must bear these duties in mind when implementing the recommendations within *Valuing People's Oral Health*. They need to ensure that there is appropriate evaluation of all programmes aimed at improving the oral health of disabled people. Strategic health authorities (SHAs) may also wish to evaluate the extent to which PCTs have adopted the recommendations set out in the document and, in the longer term, what impact these have had on oral health within disabled groups in their communities.

Next steps

Collecting information

- 8 PCTs will want to collect local epidemiological data in order to undertake appropriate oral health needs assessment as part of their commissioning of dental care services.

Evidence of improvement

- 9 The best practice guidance contained in this document is based on evidence-based guidance produced in *Delivering Better Oral Health*. It will work if implemented appropriately. In order to assess the impact on oral health in disabled groups, specific baseline information will need to be collected as part of the routine oral health epidemiological programmes co-ordinated by the Public Health Observatories.
- 10 The equality screening and Equality Impact Assessment were undertaken by Tony Jenner, Deputy Chief Dental Officer, Department of Health and validated by David Lye, Head of Dental and Eye Care Services, Department of Health.



Introduction

- 1 Oral health is important to the health and well-being of disabled children and adults. This supplement to *Choosing Better Oral Health* (Department of Health, 2005b) sets out to inform actions and advice required at every level and across organisational boundaries to prevent oral disease and protect and secure oral health for these groups.
- 2 Many oral diseases are preventable; however, it is important to acknowledge that certain circumstances can render an individual more susceptible to developing oral health problems. Actions are needed to create conditions that support and encourage good oral health.
- 3 Oral health in the UK has improved dramatically over the last 25 years, irrespective of class or geographical location. However, inequalities still exist, with communities that live in deprived areas, including the disproportionate number of people from BME backgrounds living in these areas, suffering more oral health problems. Those families that have the requisite social skills are often able to access care and respond to the preventive messages, but others may not. It is important to bear in mind that oral health status can be affected by the social environment. Additionally, what is often overlooked is the issue of 'healthcare overload' where some parents/carers of disabled children and adults may have to juggle many different appointments in various care settings; this may result in them prioritising other commitments over oral healthcare, leading to missed or cancelled dental appointments.
- 4 In addition to the influence of the social environment, some disabled children and adults may have problems in that they and their carers often need help to implement behaviours which will reduce the prevalence of the two most common problems – dental caries and periodontal disease.
- 5 The ideal preventive messages for 'at-risk' groups are clear, namely:
 - > begin brushing with a family strength fluoride toothpaste as the first teeth erupt. Children (including younger ones) at a high decay risk, such as those with an impairment or disability, should use toothpaste containing 1350–1500 ppm (parts per million) fluoride. Children under the age of three should use only a smear of toothpaste, while those aged three and over should only use a pea-sized amount. Toothbrushing should be supervised by an adult to prevent eating or licking of toothpaste at least until the age of seven. In disabled children, supervised brushing may need to continue beyond this age, depending on the individuals' dexterity and independence;
 - > continue with regular, twice-daily brushing using a family fluoride toothpaste (or pastes with higher fluoride concentrations, if appropriate);

- > promote recommended breastfeeding (www.breastfeeding.nhs.uk) and weaning practices – see the leaflet on *Weaning* (Department of Health, 2005a);
 - > ensure that night-time bottles are discontinued by 12 months of age;
 - > reduce both the frequency and amount of added sugars consumed (dietary supplements should preferably be given at mealtimes);
 - > ensure that long-term medication is sugar-free, wherever possible;
 - > ensure that supplements to alleviate the symptoms of dry mouth are provided, should this condition develop;
 - > maintain optimal denture hygiene, as appropriate; and
 - > access primary dental care services at appropriate intervals to receive evidence-informed preventive care and advice.
- 6 It is important to recognise that disabled children and adults (both those with a lifelong disability, and those who acquired a disability later in life) and their carers may encounter difficulties in implementing these good practices.
- 7 The preventive messages are essentially straightforward and can be delivered by everyone in contact with these groups. In addition, the parents and carers of at-risk individuals can be followed up to ensure that the appropriate education and resources are being provided, and that key actions to protect and improve oral health are being implemented. The fundamental task is to build a robust preventive programme to ensure that disabled children and adults maintain optimal oral health.
- 8 The vast majority of care and support is provided in the home setting by parents and carers. It is here that the preventive advice given is converted into actions, incorporated into daily routines, and has the greatest impact. It is therefore vital for PCTs to make sure that all health and social care providers are delivering consistent, evidence-informed preventive actions and advice to improve oral health.
- 9 As most dental treatment is provided in primary care, PCTs can ensure that priority is given to at-risk groups by embedding appropriate preventive programmes into local oral health strategies, in addition to ensuring that responsive, high-quality primary and secondary care dental services are in place when required. Achieving this requires that PCTs and dentists work together with other local stakeholders.
- 10 Some disabled children and adults can present challenges to primary and secondary care providers. Delivering a quality service to children and adults who may have poor understanding, uncontrolled movements, limited mouth opening, poor posture or limited mobility, who may experience tiredness during treatment or have medical problems, presents a range of difficulties and barriers.

- 11 This document is designed to complement *Choosing Better Oral Health* and should be a useful resource for commissioning managers, professional advisers, health, education and care professionals, and for service users and carers, to assist them in focusing on preventing oral disease and ensuring that dental services are of a high quality and responsive to the needs of children and adults with an impairment or disability.
- 12 The *Commissioning Tool for Special Care Dentistry* (BSDH, 2006), produced by the British Society for Disability and Oral Health (BSDH) and funded by the Department of Health, was published in December 2006 and should be considered alongside this supplement to assist in the development of responsive quality services.

Overview

- 13 Planning for actions to improve the oral health of disabled children and adults will involve an assessment of the level of need



found in these groups, compared with their non-disabled counterparts.

- 14 To enable planning of robust, effective oral health programmes for disabled children and adults, it is important to have knowledge of the prevalence and incidence of different impairments, and information concerning the epidemiology of oral disease in these at-risk groups. However, historical epidemiological studies, such as the ten-yearly national dental health surveys of children and adults and the annual children's dental health surveys co-ordinated by the NHS and British Association for the Study of Community Dentistry (BASCD), have not routinely gathered information from disabled children and adults. There is, therefore, a necessity for PCTs to carry out oral health needs assessments for these groups to facilitate the development of inclusive strategies that best serve the whole population.
- 15 A proportional estimate of the at-risk population may initially be more important than calculating absolute numbers; this data can help to inform commissioners with respect to the types of health promotion (and input required) and the service provision necessary. Table 1 suggests a menu of information sources that PCTs may find helpful to provide these estimates for their own population.

Table 1: Examples of information sources available

	For children and adolescents	For adults
Numbers with disability (this depends on the definition of disability)	<p>Local multi-agency database of children with an impairment or disability – held by social services.</p> <p>Record of children with statements of special educational needs in a year cohort – this could be extrapolated to show numbers for all aged 5–16 years.</p> <p>Numbers known to disabled children’s team.</p> <p>General estimate that 3% of children have a disability – see <i>Together From The Start</i>.¹</p> <p>Some areas will have health authority-run disability databases for children.</p>	<p>Extrapolate from child register.</p> <p>Learning disability partnerships may hold registers listing numbers of adults with learning disabilities – estimated at between 1.3% and 3.5% of the population.</p> <p>Mental health registers.</p> <p>Older persons review.²</p>
Dental treatment needs	<p>Local surveys of 5-year-olds and Year 6 children – PCT-based dental services (PCTDS) and national reports.^{3,4}</p> <p>Surveillance and local surveys of children in special needs schools – PCTDS.</p> <p>Interpolation from national Child Dental Health Survey.⁶</p>	<p>Local pilot surveys of adult groups – PCTDS (contact The Dental Observatory, Preston PCT, Preston Business Centre, Watling Street, Fulwood, Preston PR2 8DY, Tel: 01772 645626).</p> <p>Interpolation from national Adult Dental Health Survey.⁵</p>
Impact of disability and delivery of treatments	<p>This involves an assessment of the degree of difficulty in carrying out dental treatment, based on the individual’s impairment or disability and the impact this has on providing a responsive service.</p>	

Table 1: Examples of information sources available (continued)

Views of patients and the public	<p>Report of North West Stakeholder Day.⁷</p> <p>Views reported in <i>Together From The Start</i>.</p> <p>Local qualitative surveys or opinion from user groups, patient panels.</p> <p>Local family forums.</p> <p>Contact a Family, a charity for families with disabled children.⁸</p> <p>Consult with organisations supporting BME disability groups and identifying with local race and religious issues.</p>
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Notes to Table 1

- ¹ Department for Education and Skills/Department of Health (2003). *Together From The Start – Practical guidance for professionals working with disabled children (birth to third birthday) and their families*. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4007526
- ² Department of Health National Working Group for Older People (2005). Meeting the challenges of oral health for older people: a strategic review. *Gerodontology* **22**(SI): 2–48.
- ³ Pitts NB, Boyles J, Nugent ZJ et al. (2006). The dental caries experience of 11-year-old children in Great Britain. Surveys co-ordinated by the British Association for the Study of Community Dentistry in 2004/05. *Community Dental Health* **23**: 44–57.
- ⁴ Pitts NB, Boyles J, Nugent ZJ et al. (2005). The dental caries experience of 5-year-old children in England and Wales (2003/04) and Scotland (2002/03). Surveys co-ordinated by the British Association for the Study of Community Dentistry. *Community Dental Health* **22**: 46–56.
- ⁵ Office for National Statistics (2000). *Adult Dental Health Survey: Oral Health in the United Kingdom 1998*. www.statistics.gov.uk/pdfdir/dh0999.pdf
- ⁶ Office for National Statistics (2003). *Decline in obvious decay in children's permanent teeth. Children's Dental Health Survey 2003. Preliminary Findings*. www.statistics.gov.uk/children/dentalhealth
- ⁷ *Oral Health Care for People with Special Needs. Summary of main areas of concern*. Report arising from stakeholder conference, 30 November 2005. Copies are available from nancy.moss@nhs.net
- ⁸ Contact a Family (2005). *Open wide? Families' experiences of accessing dental care for their disabled child*. www.cafamily.org.uk

Causes of poor oral health and principles of good practice

- 16 Some congenital conditions and syndromes may adversely affect dental development and compromise oral health. Despite rigorous preventive programmes and intervention, it is possible that the requirement for dental treatment services will be unavoidable for some. However, good oral health is an achievable goal for the majority of disabled children and adults.

Factors affecting oral health

- 17 In order to improve oral health and reduce inequalities, the underlying causes of dental diseases need to be challenged. Six important factors involved in the aetiology of dental diseases have been described in *Choosing Better Oral Health*.

Diet and nutrition

- > Frequent, high sugar consumption is the most significant factor in developing dental decay.
- > A healthy, nutritious diet, which is low in fat, sugar and salt, and includes five or more portions of fruit and vegetables a



day is essential for maintaining good general health; this will, in turn, impact upon dental health as snacking on fruit and vegetables rather than cariogenic foods will help to reduce the risk of dental decay.

- > Excessive consumption of acidic, carbonated drinks (including those which are labelled 'diet' and 'sugar-free' and those which are spring water-based) can lead to erosion of teeth resulting in pain and the need for treatment.

Oral hygiene

- > Failure to remove dental plaque by regular toothbrushing compromises the health of the periodontal tissues, which support the teeth. Oral hygiene routines are best established in early life as part of general grooming and cleanliness.
- > In addition to brushing natural teeth, dentures need to be removed and effectively cleaned on a daily basis to maintain the health of the oral environment.

Exposure to fluorides

- > Optimal exposure to fluoride promotes remineralisation of tooth surfaces following acid attack, and is highly effective in preventing tooth decay.
- > Twice-daily use of family fluoride toothpastes and regular application of fluoride varnish are evidence-based measures which can prevent and control dental decay. Children, including younger



ones at a higher decay risk, and those with an impairment or disability should use toothpaste containing 1350–1500 ppm fluoride. Children under the age of three should use only a smear of toothpaste, while those aged three and over should only use a pea-sized amount. Toothbrushing should be supervised by an adult to prevent eating or licking of toothpaste at least until the age of seven. In disabled children, supervised brushing may need to continue beyond this age, depending on individuals' dexterity and independence.

- > Water fluoridation is an effective and safe public health intervention which has been shown to reduce the prevalence of decay in populations.

Tobacco and alcohol

- > Use of tobacco, including chewing tobacco, paan and betel, is an aetiological factor in periodontal disease and is the greatest risk factor for oral cancer.
- > Excessive alcohol consumption is a further risk for oral cancer and, when combined with smoking, has a synergistic effect.

Injury

- > Dental injuries can cause pain and facial disfigurement, which can adversely affect an individual's self-confidence and self-image.
- > Treatment for dental injuries may be prolonged and expensive.

- > Epileptic seizures and falls due to dyspraxia and impaired mobility increase the risk of traumatic dental injury, which is likely to require urgent assessment and treatment.

Other medical conditions

- > A wide range of both acute and chronic medical conditions can adversely affect oral health.
- 18 Children and adults with chronic medical conditions are at greater risk of dental disease, and any oral health problems they develop are likely to be more complicated to treat.
 - 19 Often, people who are disabled require special diets or may be malnourished, which will affect their general health and immune response. Feeding times may be prolonged and high-sugar diets may be deemed necessary in order to maximise calorie intake. They may require frequent intake of small meals and snacks, and these will often be high in simple carbohydrates, which are easily digested. Medical interventions required by a child or adult may therefore, at times, be in direct conflict with those dietary measures known to promote good oral health.
 - 20 In addition to high-sugar diets, medication taken by those with disabilities may contain large quantities of sugar and/or be acidic; the frequency and timing of intake will impact upon the individual's oral health and the medicine may also have side effects, including reduced salivary flow.

- 21 Establishing and maintaining an effective oral hygiene regime may prove difficult in at-risk groups, and carers may not fully comprehend the importance of persisting with routine toothbrushing using a family fluoride toothpaste. Poor compliance and pronounced gag reflexes may hinder attempts at maintaining a routine. Dependent adults who are reliant on carers for preventive home care may therefore experience difficulties in maintaining the best achievable oral health. Parents and carers may be concerned about intervening for adults who, because of their impairment or disability, are unable to provide consent and who may, in some instances, require clinical holding. It is important that they are reassured that they are acting in their client's best interests by implementing effective preventive oral home care.



- 22 Additional problems that increase the risk of dental disease include gastric reflux, vomiting and rumination disorder, all of which can cause dental erosion and associated discomfort. Non-oral feeders will experience specific complications in maintaining optimal oral health and comfort.
- 23 Furthermore, a lack of dental information and poor dental attendance associated with those who have chronic medical conditions or a disability will impact on their oral health. Providing education and resources to enable those with a disability to minimise or eliminate these factors in their own lives, either by themselves or with the support of carers and family, will reduce the incidence of undesirable dental conditions such as caries, periodontal disease, trauma and oral cancer, in addition to reducing the risk of systemic illness.
- 24 Primary dental healthcare professionals have a limited role in the broader social framework of disabled children and adults and therefore need to work in partnership, across professional boundaries, with a range of different social and healthcare organisations and agencies. Involvement of a wide range of 'partners in oral health' (Table 2) requires co-ordination to ensure that consistent oral health messages and education are delivered and appropriate resources are provided when necessary (see Appendix 1).



Table 2: Partners in oral health

Health professionals	For example: <ul style="list-style-type: none">> midwives> health visitors> district and practice nurses> dieticians> specialist nurse practitioners> pharmacists> school nurse advisers> speech and language therapists> doctors> hospice staff> learning disability nurses.
Childcare and education services	For example: <ul style="list-style-type: none">> childminders> pre-school and nursery staff> teachers> school governors> parent and teacher associations> catering staff.
Social care professionals	For example: <ul style="list-style-type: none">> carers> catering staff in residential care establishments and day-care centres> learning disability teams> mental health teams.
Voluntary sector	For example: <ul style="list-style-type: none">> national and local support groups for disabled children and adults.

25 PCTs need to ensure that their oral health strategy provides disabled children and adults with access to the services they need to enjoy optimal oral health. A multiprofessional approach, working in partnerships across all boundaries, will require procurement of services from a variety of healthcare professionals and local authority groups, as detailed in Table 2. A preventive oral health framework for disabled children and adults, embedded into the strategy, will:

- > improve the oral health and well-being of these groups;
- > reduce oral health inequalities;
- > ensure a better experience of care;
- > reduce the need for treatment of dental decay and periodontal disease;
- > contribute to the wider aim of safeguarding and promoting the welfare of children and vulnerable adults; and
- > ensure the early detection of oral cancer.



Improving oral health – principles of good practice

- 26 *Choosing Better Oral Health* outlined how progress against its objectives could be measured through improvements in the oral health of the population and increased delivery of high-quality preventive dental services. These are important benchmarks for disabled children and adults.
- 27 The following principles may be helpful for PCTs wishing to improve the oral health of disabled children and adults in the populations they serve:
- > Each PCT should consider having a named individual who has responsibility for championing better oral health. This person could be, depending on local circumstances, a consultant in dental public health, a clinical director for PCT dental services, a primary care dentist or another dental care professional.
 - > The appointed individual with responsibility for improving oral health in the population and commissioners of primary dental care services should set the care of disabled children and adults as a priority.
 - > The oral health of at-risk groups can only be improved if action is taken at all levels; this includes action at population level (for example adding fluoride to a water supply), and targeted approaches, health promotion and education programmes.
- > All health and social care agencies should recognise the actions that can both damage or protect oral health, and commission appropriate general and specialist services (for example paediatric dentistry and special care dentistry services*) with a preventive ethos. The appointed individual should work at all necessary levels.
 - > When developing services, it is important to have input from a specialist clinician and involvement from patients and carers who will access the services.
 - > The PCT oral health champion could lead on the formation and maintenance of



* In 2004, the Standing Dental Advisory Committee completed its review of the dental specialties and made the recommendation that the General Dental Council should **consider** the establishment of a new specialty, that of special care dentistry.

suitable partnerships between the health, social and educational sectors.

28 PCT-led partnerships should be responsible for:

- > ensuring that all health, social care, education and voluntary sector group workers acknowledge that oral health is everyone's business, especially for at-risk disabled children and adults. It is not just the responsibility of the dental profession;
- > including positive action for achieving and maintaining good oral health in all healthcare plans for disabled children and adults, that is an oral health plan embedded within the care plan;
- > providing ongoing, evidence-informed training for all health and social care workers to allow them to recognise the importance of good oral health for this group, which will allow them to:
 - give carers and clients the correct advice with regard to oral care;
 - support good habits with regard to weaning, feeding, daily oral care, sensible medication regimes and the optimal use of fluoride;
 - provide care in such a way that harm is minimised with regard to prescribing medicines, supplements and dietary advice;

- recognise when a prompt and appropriate referral to specialist care should be made; and

- ensure that appropriate protocols and systems are in place, so that this can happen;

- > disseminating information about the primary and secondary dental care services available, and how to access them, and ensuring that multilingual information or a translation service is available as appropriate; and

- > providing all primary dental care clinicians with sufficient information to ensure that high-quality care is given for this group and that they are able to deliver all evidence-informed proactive prevention.

Evidence-informed actions

29 *Choosing Better Oral Health* documented a range of good practice to improve and protect oral health. Details were presented for the underlying risk factors for oral disease and a target population and key partners were listed for every action point. Water fluoridation is an effective public health measure and has been proved to be more beneficial than fluoride toothpaste alone. All of this is relevant for disabled children and adults but additional action

focused at this target group would include the actions outlined below.

Children

Please refer to paragraph 5 for detailed advice regarding the use of fluoride toothpastes.

- > Provision of fluoride toothpaste with advice and encouragement for its use.
- > Supervised brushing with fluoride toothpaste in nurseries and schools.
- > Professional application of fluoride varnish, three to four times yearly.
- > Encouragement of twice-daily, supervised brushing with fluoride toothpaste.
- > Professional application of fissure sealants to all susceptible pits and fissures.

Adults

- > Professional application of fluoride varnish, twice yearly.
- > Encouragement of twice-daily, supervised brushing with family fluoride toothpaste with a minimum of 1350–1500 ppm fluoride (higher concentrations 2800 ppm or 5000 ppm as appropriate).
- > Provision of supplements to aid dry mouth.

30 These actions will not come about unless a robust oral care pathway is in place for all at-risk children and adults.

31 Resources are available to assist primary dental care teams to improve oral health within new contracting arrangements and include *Delivering Better Oral Health: An evidence-based toolkit for prevention* (Department of Health, 2007). PCTs need to be aware of this evidence and performance manage providers to ensure that services for disabled children and adults deliver evidence-based preventive measures and actions such as the professional application of fluoride varnish.

National Service Framework for Children, Young People and Maternity Services

32 The *National Service Framework for Children, Young People and Maternity Services* (NSF) (Department of Health, 2004a) was published alongside supporting material, which included a series of exemplar patient journeys. While oral health issues were documented, exemplars, which could address these specifically, were not included. As the framework and approach is familiar through the NSF programme, an exemplar has been produced to illustrate prevention and oral health in action (Appendix 2).

- 33 The NSF oral health themes include the importance of responding to the views of children and their parents; involving them in key decisions; providing earlier identification; diagnosis and intervention; and delivering flexible, child-centred, holistic care. They demonstrate how care can be integrated between agencies and over time and can be sensitive to individual's changing.
- 34 It is intended that the exemplar could be useful to stimulate local debate and assist multi-agency partners to re-evaluate the way they collaborate on, commission and deliver oral health interventions and services for these groups. It could be used as a multidisciplinary training tool for staff working with children and young people to raise awareness of specific issues and stimulate discussion, and could be helpful in canvassing the views of disabled children and adults on specific issues, such as good and 'not so good' aspects of the current service.

Improving oral health – making it happen

35 This section puts the guidance in the context of wider NHS reforms; it can inform commissioners of the preventive actions and responsive services with a preventive ethos required for disabled children and adults.

36 The main functions of a PCT as detailed by the Department of Health are:

- > engaging with its local population to improve health and well-being;
- > commissioning a comprehensive and equitable range of high-quality, responsive and efficient services, within allocated resources, across all service sectors; and
- > directly providing high-quality, responsive and efficient services where this gives best value.

PCTs need to assess their progress in achieving these functions with regard to oral health and dental services for disabled children and adults.

37 *Health Reform in England: Update and Commissioning Framework* (Department of Health, 2006c) provided an update about health reform and focused on commissioning NHS services. It set out a framework detailing key changes designed to strengthen commissioning and ensure that commissioning drives health reform and improved health and healthcare. A vision 'to develop a patient-led NHS that uses available resources as effectively and fairly as possible to promote health, reduce

inequalities and deliver the best and safest possible healthcare' was stated. It is acknowledged that health services are not 'one size fits all'. It is necessary to improve and secure oral health for children and adults with impairments and disability in order to meet the stated objectives. The wider objectives are to:

- > improve health and well-being and reduce health inequalities and social exclusion;
- > secure a comprehensive range of preventive actions and services;
- > improve the quality, effectiveness and efficiency of preventive programmes and services;
- > increase choice for patients and ensure a better experience of care through greater responsiveness to people's needs; and
- > achieve best value within the resources provided.

38 The *Commissioning Framework for Health and Well-being* (Department of Health, 2007b) signals a clear commitment to greater choice and innovation. Its key aims are to achieve:

- > a shift towards services sensitive to need, which maintain independence and dignity;
- > a reorientation towards promoting health and investing now to reduce future ill health; and
- > a stronger focus on commissioning services that will achieve better health,

with everyone working to promote inclusion and tackle inequalities.

- 39 Overall, a patient-centred approach is required, as detailed in the Department of Health publications *Commissioning a Patient-led NHS* (2005c) and *Our Health, Our Care, Our Say* (2006a). SHAs will manage the effectiveness of this approach through their oversight.
- 40 A model of best practice for the integration of specialist and generalist care to provide special care dentistry can be found on the BSDH website (www.bsdh.org.uk.) This model demonstrates the importance of commissioning specialist dental services and identifies many other partners that may be involved in a patient care pathway.
- 41 PCTs and dentists will need to work together. Effective joint planning and commissioning is at the heart of improving outcomes for the oral care of vulnerable groups. PCTs need to acknowledge and manage the challenges that primary care dental practitioners face in accepting and treating some disabled children and adults, for example longer appointment times may be required. Regard will also need to be paid to the preventive needs of these patients. PCTs should, where appropriate, develop a local 'clinical network' suitable for the delivery of necessary services. Dissemination of information with respect to these services is best practice as is all care being provided by locally agreed protocols and policies, developed following evidence-

based national guidelines and standards of care and outcomes performance managed by PCTs and overseen by SHAs.

- 42 Although dental teams will be involved in oral health promotion, prevention and delivery of care, they also have an important role in developing knowledge and skills for other workforce groups to ensure that disabled children and adults receive consistent, appropriate, evidence-informed advice and actions to improve and secure oral health regardless of setting. All dental teams should have knowledge of the needs and requirements of the Mental Capacity Act 2005 (MCA) and the Disability Discrimination Act (DDA) 1995.



- 43 The MCA provides a statutory framework to empower and protect people who are not able to make their own decisions. It makes it clear who can take decisions, in which situations, and how they should go about this. It also enables people to plan ahead for a time when they may lose capacity. It is important that dental teams are aware of the MCA to ensure that people with more complex disabilities do not find themselves denied access to treatment because dentists believe they cannot treat without overt consent. The principles underpinning the Act include a presumption of capacity, unless proven otherwise, to enable adults to make decisions on their own behalf; and a requirement to maximise decision-making capacity so that adults who require additional support to enable them to make their own decisions receive this, rather than being assessed as lacking capacity. Additionally, individuals retain the right to make what might be seen as unconventional decisions, and anything that is done for (or on the behalf) of people who lack capacity must be in their best interests and should be least restrictive of their basic rights and freedoms.
- 44 The DDA sets out the legal requirements of service providers to ensure that practices, policies or procedures do not make it impossible or unreasonably difficult to use a service. There is a requirement to provide auxiliary aids or services and to overcome physical features that may present a barrier to disabled people wishing to use a service. The Disability Equality Duty sets out the legal obligation of all public sector organisations to promote equality of opportunity for disabled people. In addition to ensuring that disabled people are treated fairly, the law requires organisations to include them in decision making and impact assessments.
- 45 General dental practices are the focal point of a fully integrated preventive care pathway. The critical issue is appropriate patient care and, for some disabled children and adults, specialist care may be indicated. However, there is a need to ensure that the local dental practice is available and accessible to those who do not require specialist care routinely. Inclusion in all aspects of society is vitally important and accessing dental care locally is no exception.
- 46 In addition to commissioning preventive interventions to improve oral health, PCTs need to consider the following key actions to secure and improve oral health when planning dental care services for children and adults with an impairment or disability:
- > Provision of accessible, responsive primary care dental services and monitoring of these to ensure that evidence-informed preventive intervention is being delivered.
 - > Provision of responsive care, involving a specialist when necessary.
 - > Timely access to secondary and tertiary care when required.

- > Provision of general anaesthetic services and sedation services which meet the needs of disabled children and adults. These services need to be responsive to those with acute pain and who require an urgent general anaesthetic.
- > Involvement of users and carers, and advice from appropriate specialists in developing services.
- > Provision of responsive, urgent and out-of-hours care.
- > Provision of clear, accessible and, where appropriate, multilingual information. A range of technologies are available to help with this; links to help organisations improve their communication can be found on the Valuing People website (<http://valuingpeople.gov.uk/dynamic/valuingpeople77.jsp>).
- > Integrated care pathways highlighting special circumstances.
- > **Oral healthcare included in *all* care plans.**



Good practice

Case study 1: Oral health information for parents of chronically ill children

- 47 A Vocational Dental Practitioner Project, which was carried out by Bracknell Forest PCT Community Dental Service in 2006, involved paediatricians and dieticians working to encourage consistent dental health education advice for children with chronic illnesses or on high-sugar/calorie diets.
- 48 The project aimed to:
- > assess and provide evidence of the need for preventive advice aimed at the target group;
 - > create a tool (in the form of an oral health education leaflet) for dieticians, paediatricians and other health professionals to use when discussing oral health with parents;
 - > educate parents about the importance of good oral health from an early stage in cases where children were chronically ill or required special diets;
 - > encourage communication of consistent messages from all dental and medical services; and
 - > produce local recommendations on prevention strategies and future projects to increase multidisciplinary involvement in dental health.
- 49 Stages:
- > Open discussions with paediatricians and dieticians.
 - > Assessment of the health information given out routinely by paediatricians and dieticians, and the risk that this may contravene preventive dental advice.
 - > Acquisition of local data pertaining to children aged 0–17 treated in dietetics departments (number treated, what they were treated for and where they were treated).
 - > Finally, creation of an oral health education leaflet aimed specifically at preventing dental disease in chronically ill children and those requiring high-sugar diets.
- 50 It was evident that children with chronic medical conditions, or those requiring dietary intervention, were a population at high risk of developing dental disease. The health leaflets available regarding dietary advice for children requiring high-sugar/calorie diets or those with chronic medical conditions contained information that increased the risk of dental disease; little or no preventive dental advice was offered in conjunction with the distribution of these.

- 51 The health professionals involved in the project were keen to provide effective oral health advice to their patients, whom they felt would greatly benefit from a more multiprofessional approach.
- 52 The ensuing oral health education leaflet, which was created with the support of dieticians and paediatricians, became an educational tool for all healthcare professionals involved in children's care; the main message, aimed at the parents and carers of children with chronic disease or requiring high-calorie diets, is that prevention of dental disease is possible without changing the underlying dietary advice from dieticians or paediatricians.
- 53 The leaflet was distributed in paediatric outpatient departments and wards where most patient contacts were made.
- 54 The leaflet can be accessed electronically at: www.heatherwoodandwexham.nhs.uk/patient_info/information_leaflets/dental.pdf
- 55 The health professionals involved in the project were keen to provide effective oral health advice to their patients, whom they felt would greatly benefit from a more multiprofessional approach.
- 56 Clinical examination confirmed the patient to be free of dental caries. However, oral hygiene was very poor, with an extensive accumulation of plaque and calculus covering all tooth surfaces.
- 57 The carer, who supported the patient, assured the dentist that his client was provided with a toothbrush and toothpaste twice a day. Unfortunately, the patient was not able to brush his teeth without active support and intervention. The carer was alerted to this problem and to the potential for deterioration of his client's dental health.
- 58 Further to this visit, the patient's healthcare plan was amended to include a section on oral health. The support the patient required from the carer was detailed and the carer was provided with training in tooth brushing and oral hygiene education, in order to support his client.
- 59 A review appointment two weeks later confirmed a significant improvement in the patient's oral hygiene. Dental examinations at regular intervals, including reinforcement of preventive advice, can be provided within local primary care dental services.
- 60 This case highlights the importance of incorporating oral care into all healthcare plans.

Case study 2: The importance of oral care in the overall healthcare plan

- 55 A 37-year-old man with moderate learning disabilities was referred, by his social worker, to the local PCT dental service (PCTDS) at Central Lancashire PCT, which has a department of special care dentistry, for a dental examination.
- 60 This case highlights the importance of incorporating oral care into all healthcare plans.

Case study 3: Suggestions received from the lay-user perspective to assist with service planning

- 61 Suggestions received include:
- > giving patients and their parents/carers clear advice in plain, simple language regarding preventive actions they can take;
 - > involving patients with disabilities and their carers in the discussions and decisions regarding management of appointment schedules to offer choice and avoid 'healthcare overload';
 - > setting up systems to ensure that patients who have received specialist care are followed up and not 'lost' on return to primary care practitioners;
 - > encouraging patient-based evaluation – to enable identification of the 'good experiences', as well as those areas that haven't worked so well;
 - > being mindful of the amount of paperwork sent out to the patient with appointment cards etc. Ensure that this is user friendly with clear, simple instructions about how it should be completed;
 - > providing a photograph of the surgery, dentist and dental team to help parents/carers prepare patients for the experience of attending the clinic;
 - > including a section for provision of details of 'abilities', as well as relevant 'disabilities', on referral forms;

- > ensuring that all members of the dental team know how the disability affects the patient; and
- > ensuring that flowcharts illustrating treatment pathways cover a maximum of one side of A4 and are user friendly with simple details.

Case study 4: Example of good preventive practice

- 62 An epidemiological survey in Manchester revealed that five-year-olds attending special needs schools had far higher levels of dental decay and tooth extractions due to disease than children attending local mainstream schools.
- 63 Subsequently, a supervised brushing scheme was introduced to all special schools in the local area and toothbrushes, brush holders and family fluoride toothpaste (1350–1500 ppm fluoride) were provided for all children to use on a daily basis. Every school day, all the children had their teeth brushed, or were supervised and helped while they did this for themselves. Paste was dispensed by school staff with only a small pea-sized blob being put onto the brush for those aged under seven. School staff used the opportunity to teach about numbers, colours, listening to instructions, and starting and completing a task.

- 64 In order to reinforce the importance of twice-daily brushing at home, gift bags of family fluoride toothpaste, a brush and a leaflet were provided for each child to take home for each longer school holiday.
- 65 The schools involved are supportive of the scheme because they had been keen to do something to improve the poor dental health of the pupils in their care, and parents are in favour as their children have generally become more accepting of the daily routine of tooth brushing.
- 66 This scheme is evidence based, using materials in such a way as to maximise their effect while minimising risk, and it provides a means by which educational messages can be put into action. In this way it is unlikely to increase inequalities in health.

Appendix 1: Provision of oral care for disabled children and adults

The common risk approach recognises that chronic non-communicable diseases such as, for example, obesity, heart disease and oral disease share a set of common risks, conditions and factors. It is essential that those outside the dental team are involved in the promotion of good oral health.

Improving oral health for people with disabilities is not just brought about by the dental team. Oral health promotion and prevention of oral disease should be reinforced by health education and social care professionals as part of the general care of this group of people. For example, dieticians must be aware of the impact on a child's teeth when they advise high-calorie supplements for children; carers of adults with learning disabilities must be aware that if they do not brush the teeth of an adult with a learning disability who is unable to do it him/herself, they will allow the development of disease. Once oral disease develops, it may be very much more difficult to treat in people with limited understanding and complex medical conditions.

Factors influencing changes in the population of disabled children and adults which will have an impact on the provision of dental services and oral care for these at-risk groups include:

- > lower mortality rates of children with complex and multiple disabilities and increasing numbers surviving into adulthood;
- > higher than average morbidity rates of children born prematurely;
- > increased life expectancy of people with disabilities;
- > the increasing prevalence of disability among some ethnic minority groups;
- > improvements in medical care leading to increased survival rates for those with chronic medical problems, impairment or disability;
- > increasing numbers of people with learning disabilities facing the challenges of older life;
- > an increasing number of older people who are more likely to develop disabilities coincidental or consequent to their age;

- > increasing numbers of patients with complex or chronic medical conditions, impairment or disability, which presents a challenge to service providers;
- > maintaining oral health and complex restorations, which becomes a huge challenge when the status quo of personal oral care is affected by disability;
- > a cultural value shift away from the acceptability of total tooth loss as part of the ageing process to retaining the natural dentition;
- > a demographic shift from the loss of teeth to increased retention of natural teeth so that more teeth are at risk of dental disease in the older population;
- > changing public expectations regarding the importance of appearance, possibly leading to increased requests for implants, orthodontics and cosmetic dentistry from disabled people;
- > increasing numbers of patients with multi-faceted medical histories or disabilities and impairments, who are unsuitable for day-case surgery and require inpatient admission for dental treatment;
- > increased awareness of the availability of conscious sedation, possibly leading to increased requests for dental treatment sedation services from disabled people;
- > post-radiotherapy effects in those treated for head and neck cancers, which can result in rampant decay and post-extraction osteomyelitis; and
- > the need to provide consistency as patients progress from children's services to adult services.

Appendix 2: Dental care exemplar for a disabled child

Dental journey	Children’s NSF standard	Evidence/links
<p>First year</p> <p>Jake is delivered normally at full term. His parents receive support and information from the antenatal team, including oral health advice. He has routine developmental checks at the local health centre.</p> <p>His mother asks advice about feeding, as Jake seems reluctant to try different tastes. Advice given by his health visitor takes account of the need to encourage habits that will help care for his teeth.</p> <p>Jake’s health visitor gives him a toothbrush and toothpaste (1350–1500 ppm fluoride) pack and asks if he attends a dentist. His mother says she will take him with her.</p>	<p>Standard 1 – promoting health and identifying needs.</p>	<p>Brushing for Life initiative to tackle dental caries in children living in deprived areas.</p> <p>Healthcare workers trained in oral health promotion distribute toothbrush and toothpaste packs from health centres or Sure Start centres.</p>
<p>Before diagnosis</p> <p>Jake’s parents take him to their general dental practitioner (GDP). The dentist gives advice on caring for children’s teeth and encourages the use of a drinking cup instead of a bottle.</p> <p>Six-monthly check-ups are advised and fluoride varnish is applied to his teeth. As he is reluctant to sit in the dental chair, this is done while he sits on his father’s lap. His parents are shown how to brush his teeth.</p> <p>The dentist makes an entry in his personal child health record.</p>	<p>Standard 2 – supporting parents in their caring role.</p> <p>Standard 1 – prevention and early intervention.</p>	<p>Richards, 2006.</p> <p>Scottish Intercollegiate Guidelines Network, 2005.</p>

Dental journey	Children's NSF standard	Evidence/links
<p>Diagnosis of autistic spectrum disorder aged 3½ years</p> <p>Jake's mother phones the dental practice to explain that since his last visit Jake has been diagnosed with autistic spectrum disorder. She is worried that he may not be allowed to come to this dentist any longer. The receptionist reassures her that there will be no problem and encourages her to discuss any concerns at the next visit.</p> <p>At the next dental visit, Jake's parents explain that they are concerned that his communication difficulties may make dental care difficult.</p> <p>The dentist reassures them that the preventive measures in place will reduce the need for active clinical interventions, but should this be required a referral to the special care dental team could be arranged if difficulties became apparent.</p>	<p>Standards 3 and 8 – integrated co-ordinated care.</p> <p>Standards 2 and 8 – proactively seek to support parents and listen to parents' concerns.</p> <p>Standard 8 – information on services.</p>	<p>British Association for Community Child Health, Child Development and Disability Group, 1999. www.bacdis.org.uk</p>
<p>Primary school years</p> <p>At each visit Jake slowly becomes more confident. He now sits in the dental chair and continues to receive topical fluoride varnish at six-monthly intervals.</p> <p>Appointments are offered outside school hours and are scheduled so that he is not likely to be kept waiting.</p> <p>The dentist advises that Jake should have his newly erupted first permanent molars fissure sealed to prevent decay.</p> <p>His mother explains that she sometimes finds it helpful to use pictures to help him prepare in advance for new situations. She asks if the dental team know of anything suitable.</p>	<p>Standard 8 – access to primary healthcare appointments that meet children's needs.</p> <p>Standard 8 – provision of information in appropriate formats.</p>	<p>Uribe, 2004. Nunn, Murray, Smallridge and BSPD, 2000.</p>

Dental journey	Children's NSF standard	Evidence/links
<p>Primary school years</p> <p>The dental nurse explains that resources, which include a printed sheet of cartoons illustrating procedures, are available at the child development centre, and rings ahead to ensure that they are available at their next visit. Members of the dental team use the 'autism' section of a learning programme to update their knowledge.</p> <p>At the next appointment, despite careful introduction and explanation of new equipment and procedures, Jake becomes distressed at the sound of the suction. It seems clear that he will need more time before he is ready for this procedure. The dentist discusses this with his parents and it is agreed to refer him to the local PCT dental service, where staff are known to have expertise in treating anxious children and those with an impairment or disability.</p>	<p>Standards 3 and 8 – parents involved in decisions affecting their children.</p>	<p>Homefirst Community Trust, 1999.</p> <p><i>The Hospital Communication Book.</i></p> <p>Fiske and Davies, 2005.</p> <p>PCT dental services provide dental care for children and adults with special care needs.</p>
<p>Referral to specialist dental service</p> <p>An appointment is made for Jake to attend a specialist paediatric dentist. Jake's parents are invited to complete and return a form prior to his appointment to make the dentist aware of any aspects of dental care that may distress him.</p> <p>After several visits, Jake has his lower permanent molars fissure sealed but the upper teeth cannot be sealed successfully.</p> <p>Appointments are made to reinforce advice on preventing decay and for fluoride applications.</p> <p>At a subsequent visit, clinical intervention is required, as Jake has sustained trauma to an anterior tooth. A general anaesthetic (GA) is required for necessary treatment.</p>	<p>Standard 1 – early diagnosis and early intervention.</p>	<p>National Autistic Society, <i>Dental Care and Autism</i> (leaflet). (Also available in Fiske and Davies, 2005.)</p>

Dental journey	Children's NSF standard	Evidence/links
<p>Referral for dental treatment under GA</p> <p>The specialist dentist is able to place Jake directly on the waiting list for dental treatment under GA at the local hospital. A suggested treatment plan is discussed with Jake, his parents and the specialist paediatric dentist who will carry out the treatment.</p> <p>A further appointment is made with the dental team for preventive advice and care. The team is aware that Jake is currently seeing a community dietician due to the electronic information-sharing index. The team can be confident that consistent, appropriate advice is given.</p> <p>The team is also aware that co-ordinated, supervised toothbrushing programmes are in place in Jake's school and that he is encouraged to participate in these.</p> <p>Jake has his treatment carried out under GA as a hospital day case. Staff understand and support his communication needs. The discharge summaries are sent to medical and dental primary care practitioners.</p> <p>The specialist dentist agrees to provide shared care with the GDP if necessary with regard to the traumatised tooth. Jake will continue to attend his GDP every six months.</p>	<p>Standard 8 – co-ordination of healthcare and seamless integrated working.</p> <p>Standard 7 – quality care for disabled children in hospital.</p> <p>Standard 3 – information sharing.</p>	<p>Online information sharing indices aim to improve communication between professionals who provide services for children.</p> <p>For more information and case studies from trailblazer local authorities, see: www.everychildmatters.gov.uk</p> <p>Or see an example such as Sheffield SafetyNET: www.sheffieldsafetynet.gov.uk</p>

Dental journey	Children's NSF standard	Evidence/links
<p>Secondary school years and shared care with GDP</p> <p>Jake continues to attend his primary dental care practitioner every six months. He builds up a good relationship with his GDP and, in time, is able to have simple procedures such as radiographs without difficulty. Complications with his traumatised tooth require a period of shared care with special care dentistry.</p> <p>His dentists begin to discuss with his parents the different options for his future dental care. Jake is involved in the discussions and is invited to express his own preference.</p>	<p>Standard 8 – planning for transition to adult services.</p>	
<p>Transition to adult services</p> <p>Jake continues to attend for check-ups with his GDP. At 16 he is prescribed 2800 ppm fluoride toothpaste and fluoride varnish application is continued. His key worker continues to support and implement advice given.</p> <p>The multidisciplinary approach to preventive management and the co-ordination of care by an oral health champion minimise Jake's risk of developing dental caries.</p>	<p>Standards 4 and 8 – access to age-appropriate services responsive to the young person's needs.</p>	<p>Department of Health, 2006b and 2006d.</p>

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Appendix 4: Glossary

BASCD	British Association for the Study of Community Dentistry. www.bascd.org
BDA	British Dental Association. www.bda.org
BSDH	British Society for Disability and Oral Health. www.bsdh.org.uk
BSPD	British Society of Paediatric Dentistry. www.bspd.co.uk
DDA	Disability Discrimination Act 1995. www.opsi.gov.uk/acts/acts1995/1995050.htm
Fissure sealant	Plastic/resin coating applied to the pits and grooves in the tooth surface to prevent decay.
GDP	General dental practitioner.
Local champion for oral health	An ardent supporter of better oral health for those with an impairment or disability who defends the rights of these vulnerable groups with respect to access to and provision of evidence-based preventive programmes and appropriate, responsive dental services. This person could be, depending on local circumstances, a consultant in dental public health, a clinical director for PCT dental services, a primary care dentist, or other.
NICE	National Institute for Health and Clinical Excellence. www.nice.org.uk
NSF	National Service Framework. www.dh.gov.uk/en/Policyandguidance/HealthandSocialcaretopics/DH_4070951

Paediatric dentistry consultant	A dentist who has completed specialist-level training and who has trained for an additional two years. They are examined in their higher professional training – an additional requirement to that of specialists.
Paediatric dentistry specialist	A dentist with specialised knowledge and experience in the oral and dental care of children. Many have additional qualifications and have demonstrated a minimum of three years' specialist-level training (or demonstrable equivalent) in order to be included in the Paediatric Dentistry Specialist Register held by the General Dental Council.
PCT	Primary care trust.
PCTDS	Primary care trust-based dental services.
ppm	Parts per million, for example of fluoride. A measure used to denote the fluoride content of toothpastes and mouthwashes.
RCS	Royal College of Surgeons of England. The college supervises specialist training in approved posts and examines trainees to ensure the highest possible standards. www.rcseng.ac.uk
SIGN	Scottish Intercollegiate Guidelines Network. www.sign.ac.uk
Synergistic	Two or more factors working together, so that the total effect is greater than the separate effect of the individual factors.

Appendix 5: Working group members

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Stephen Fayle	British Society of Paediatric Dentistry
Sue Greening	British Society for Disability and Oral Health
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